Journal of Accessibility and Design for All

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

PARENTS' PERCEPTIONS OF THE IMPACT OF THE HOME ENVIRONMENT ON YOUTH LIVING WITH AN AUTISM SPECTRUM DISORDER

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Received: 2021-06-18 | Accepted: 2023-02-22 | Published: 2023-05-31

***Abstract*: Background:** The prevalence of autism spectrum disorders (ASD) is estimated at 1% worldwide. People living with ASDs are often very sensitive to environmental stimuli (e.g., noise). These stimuli influence the person-environment interaction in a positive or negative way, and an excess of stimuli could cause inappropriate or unexpected behavioural responses (e.g., crisis). The Model of Competence, explaining the person-environment relationship, is the conceptual framework chosen to guide this study. The objective is to explore parents' perceptions regarding the influence of the home environment characteristics on persons living with ASD. **Methods:** A qualitative interpretive description design was used. Parents of youth with an ASD who lived in the family home until at least 16 years old participated in the study. Focus groups were conducted until data saturation. A thematic analysis was performed. **Results:** The elements impacting people living with an ASD are grouped under two themes: Non-human Environment and Human Environment. Although these elements have various effects on this population, noise, excess visual stimuli, unexpected

visitors, and changes in the environment seem to be disturbing elements. Natural light, nature, a safe environment, and stability in the environment seem to have positive effects. **Discussion:** Even though the home environment is usually a safe and stable environment, these elements emerged as fundamental. Thus, the repercussions of this in other environments that are difficult to control should be something to reflect on. **Conclusions:** Identifying these elements and their effects allows for a better understanding of the interaction between the person with ASD and their environment, both human and non-human, guiding professionals in their interventions.

Keywords: Neurodevelopment disorders, Person-Environment Interaction, Adaptation, Architectural accessibility.

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder whose prevalence has increased significantly in recent years (Fombonne, 2003; Gouvernement du Canada, 2018). Currently, 1 in 100 people worldwide lives with an ASD (American Psychiatric Association, 2015; Howlin & Moss, 2012). In Canada, 1 in 66 children have an ASD, and for adults, the estimated prevalence is 1 in 94 (Autisme Quebec, 2019). According to the Public Health Agency of Canada (2018), ASD affects boys more often than girls. In Europe, the prevalence varies across the countries; prevalence rates varied from 1.9/10000 to 72.6/10000 (Elsabbagh et al., 2012) and from 44/10000 to 197/10000 in children aged 7-9 years (Autism Spectrum Disorders in the European Union - ASDEU, 2018). According to The British Medical Association, in October 2020, it was estimated that around 700000 people in the UK had a diagnosis of autism, and one in 100 children in the UK have a diagnosis of autism spectrum disorder (British Medical Association, 2021).

As defined in the Diagnostic and Statistical Manual of Mental Disorders - 5 (DSM-5), autism spectrum disorder is a neurodevelopmental disorder with two categories of manifestations: 1) deficits in communication skills and social interactions, and 2) restricted and repetitive behaviours, interests, or activities.

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ASDs are sometimes associated with intellectual disability but may also be associated with language impairments and anxiety disorders (American Psychiatric Association, 2015). The manifestations of ASDs are heterogeneous and have different levels of severity. Its course over time may also vary from person to person (Charman, 2014; Nazeer & Ghaziuddin, 2012). People living with ASDs may experience difficulties in daily living activities and have significant disabilities and therefore require care and support (Organisation Mondiale de la Santé, 2019).

The quality of life of adults with ASDs is lower than the general population, and the environment could influence it (Mason et al., 2018; McConachie et al., 2018). People with ASDs may be more sensitive to sensory stimuli from the environment, including noise or excessive visual stimuli (Arnaiz Sánchez et al., 2011; Ludlow & Wilkins, 2009; Mostafa, 2008), however these, are only two examples of some of the many factors that can affect their lives such as textures, colours, type of lighting, or the shape of objects (Mostafa, 2014; Pfeiffer et al., 2017). Some elements may be regarded as offensive to the individual (e.g., noise) as may promote starting a crisis or inappropriate behaviours (Pfeiffer et al., 2005).

Hyporesponsiveness to pain (e.g., not showing signs of pain in the presence of an injury) and attempts to self-harm are common behaviours in this population, therefore environmental safety becomes particularly important (Arnaiz Sánchez et al., 2011; Mostafa, 2015; Richards et al., 2012). Several studies have shown that the behaviours of children with ASDs vary according to the context (i.e. Brown & Dunn, 2010; Kirby et al., 2017). For example, seeking sensory stimuli appears to be related to a play context, whereas hyper-responsiveness to sensory stimuli is more likely to occur during activities of daily living (e.g., covering one's ears from the sound of running water from the tap) (Kirby et al., 2017).

Most of the person-environment interaction research on ASD has been conducted on children at schools (i.e. Mostafa, 2014). However, there has been little research on the home environment of adults living with ASDs. The home environment is where the person lives and includes the human environment (e.g. parents, siblings) as well as the non-human environment (e.g. house, apartment). For the purpose of this study, residential institutions will not be included in the

concept of home environment. Since the behaviours of individuals with ASDs vary depending on the context, exploration of the home environment becomes of utmost importance. In addition, since the manifestations of ASDs persist throughout a lifetime (Organisation Mondiale de la Santé, 2019), it is necessary to identify the environmental characteristics that may affect the adults living with ASDto be able to provide more accurate interventions from health professionals. To do this, the information provided by the human environment can be very useful. Parents' perceptions are related to their experience as caregivers living in the same home as their children with ASD.

Since the environment has an impact on a person's activities and roles, this study is based on the Model of Competence (Rousseau, 2017; Rousseau et al., 2002). This model explains the interaction between the person and the environment through six concepts: person, environment (human and non-human), activities, roles, competence situation, and handicap situation. Activities and roles represent the interaction; thus, the person is situated in a continuum of competence situation or handicap situation, according to success or failure in the activities and roles. The environment can provide negative or positive stimuli to the person (Rousseau et al., 2002). In this study, the person is represented by the adult living with ASD, the human environment by other people living in the same home (e.g., parents) and the non-human environment by the physical elements of the home. Activities and roles are respectively represented by the interaction between the person and his/her non-human home environment and his/her human home environment.

The purpose of this study is to explore the parents' perceptions of youth living with ASD about the home environment characteristics (human and non-human) that influence their behaviours.

Methods

The following is a qualitative interpretive description research (Thorne, 2016) using the focus group technique (Krueger & Casey, 2015). The research questions were: 1) What are the elements of the human and non-human home environment

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that influence the behaviour of youth with ASD? 2) How do these elements influence their activities and roles? In order to address these questions, the following sections will present 1) the participants that we recruited, 2) the data collection process, and 3) the analysis of the data.

Recruitment and participants

The selection criteria were: 1) to be a parent of a youth living with an ASD who had lived with his or her parents at least until the age of 16, and 2) to communicate in French. Only one parent per youth was included. In this way, the criteria of homogeneity (having a child living with an ASD) and heterogeneity (different families) of participants were met (Krueger & Casey, 2015).

Participants were recruited through the Association Autisme Québec, the organisation Regroupement des organismes de personnes handicapées de la région 03 (ROP-03) and social networks. Sampling is non-probabilistic, by network (snowball type) (Fortin & Gagnon, 2016).

An information document explaining the study and the eligibility criteria for participation was distributed to each organization and on Facebook groups related to ASD. The document included the contact information of the person responsible for recruitment so that interested people could reach her by email or telephone. Interested individuals were contacted by telephone to verify their eligibility and availability for the study. Once their verbal consent to participate in the study was obtained, a socio-demographic questionnaire was then sent to them by email. Finally, the consent form was signed at the time of the group meeting.

Twelve participants (n=12) were recruited and participated in the study, including ten women (83.33%) and two men. The mean age of the participants was 53.3 years. Ten participants had paid employment at the time of data collection, one participant had unpaid employment, and one participant was unemployed (see Table 1). Four participants reported that their employment relationships had been compromised because of their role as caregivers to their

children with ASD. The mean age of children of participants living with ASD at the time of the interviews was 22.9 years (see Table 2).

Table 1. Socio-demographic data of participants (parents) at the time of the interviews.

Socio-demographic variables	N	Mean (range)	%
Age (years)	12	53,3 (41-68)	
Sex - Woman	10		83,33%
Sex - Man	2		16,67%
Employment Status - Paid employment	10		83,33%
Employment Status - Unpaid employment	1		8,33%
Employment Status - Unemployed	1		8,33%
Type of accommodation - House	9		75%
Type of accommodation - Apartment	3		25%
Home adaptations	5		41,67%
No home adaptations	7		53,33%

Table 2. Socio-demographic data of participants' children at the time of the interviews.

Socio-demographic variables	N	Mean (range)	%
Age (years)	12	22,9 (18-38)	
Sex - Woman	5		41,67%
Sex - Man	7		53,33%
Employment Status - Paid employment	1		8,33%
Employment Status - Unpaid employment	1		8,33%

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Socio-demographic variables	N	Mean (range)	%
Employment Status - Unemployed	10		83,33%
Adults with other conditions (in addition to ASD)	9		75%
Adults without other conditions (in addition to ASD)	3		25%

Data collection

Focus groups were the preferred method of data collection. The meetings took place at the <<location >> at different intervals and in the evening after work to allow parents to attend. In each session, there was a moderator and an assistant to the moderator. The moderator was a research professional and a doctoral student with experience conducting focus groups. The assistant moderator, a master's student, took notes throughout the meetings to supplement the information obtained from the recording. She presented a synthesis at the end of each meeting to validate the elements mentioned by the participants. The interview guide used by the moderator, was composed of open-ended questions and was based on the conceptual framework of the study and the recommendations of Krueger and Casey (2015), consisting on: opening, introductory, transitional, key, and final questions. Examples of key questions included: 1) Reflect on your child's behaviour at home. Could you list at least five elements of the human environment that are most influential on your child's behaviour, both positive and negative; 2) Reflect on your child's behaviour at home. Could you list at least five elements of the non-human environment that have the most influence on your child's behaviour, both positive and negative? 3) If you could build the ideal home for your child and family from the very beginning, what would it be like?

Data saturation was reached after three groups. Each group consisted of two to seven participants (Krueger & Casey, 2015; Stewart & Shamdasani, 1990): one group of seven participants and the other two groups of three and two participants, respectively. Following the first focus group, two reasons

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influenced the choice of smaller groups: 1) the nature of the subject favoured elaborate interventions by the participants, so smaller groups allowed participants to express themselves better (Krueger & Casey, 2015; Stewart & Shamdasani, 1990); and 2) recruitment difficulties (lack of participants). Group sessions ranged in length from 130 to 146 minutes, and all meetings were recorded (audio).

Data analysis

A thematic content analysis (Miles et al., 2014) was conducted. First, the audio recording was transcribed verbatim. A list of codes, based on the concepts of the Model of Competence (Rousseau et al., 2002) and relevant elements from the scientific literature on ASD, environment, and P-E interaction, was created beforehand. Based on the data collected, two new codes were added to the list to cover content related to environmental safety and resources available to people living with ASD. The coding was validated on text extracts done separately by two authors, and an agreement of 73% was obtained. This percentage is explained by the overlap of some codes, produced by the level of specificity of the codes (general codes including more specific ones).

The transcripts were coded using Nvivo software (QSR International, 2018). Subsequently, data reduction was performed in three phases (R1-R2-R3), depending on the codes. This reduction allowed the identification of themes and sub-themes (Creswell, 2014; Miles et al., 2014). For example, during the first reduction phase (R1), a table was created with the first code of some extracts of the verbatim. Then after discussing the associations of the different codes with the research team, some of the extracts of verbatim were moved to another more relevant new code. All four authors of this manuscript participated actively in all the reduction steps.

Ethical approval was obtained from the rehabilitation and social inclusion sectorial research committee of the Centre intégré universitaire de santé et de services sociaux— Capitale-Nationale (#2017-554).

Results

The results answer the two research questions: 1) What are the elements of the human and non-human home environment that influence the behaviour of youth with ASD? 2) How do these elements influence their activities and roles? The results are grouped under two main themes: 1) the non-human environment and 2) the human environment.

NON-HUMAN ENVIRONMENT

Under this theme, there are two categories of elements: 1) sensory, and 2) related to the coherence and the security of the environment.

Sensory elements

All these elements include visual, sound, olfactory, tactile and proprioceptive stimuli. However, the visual and sound stimuli stand out, as they are the ones most discussed by the participants.

Visual and sound stimuli

Participants considered that certain elements of the non-human environment can have a sensory overload effect. For example, bright colours would be disruptive. "[In his room]: a yellow then a blue with a stripe of cars for children. It was very stimulating there. The yellow one was more like mustard, ... It was beautiful, but he didn't have a good night' sleep." (P010)

In addition, cluttered spaces also appear to be a problem for adults with ASDs who prefer clean, functional spaces. For this reason, purely decorative elements do not seem to be adequate since they may overstimulate them. Discomfort, fatigue, and anxiety often appear in adults with ASDs when they are in an environment with too many visual stimuli. For example, too many colours in the same room or a crowded environment: "It has to be tidy because if there are too many things in the visual environment, it stimulates the brain too much." (P005).

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All participants noted that sounds have a significant impact on people living with ASDs. Noises of various kinds (e.g., loud and shrill, continuous, noise from appliances or compressors, screams) are disturbing to them, causing, in some cases, a handicap situation. One participant mentioned:

> The noise of the fridge, the noise of the appliances... That is our big problem, (...) she turns off her fridge and almost turns off her heating in winter. That's why I don't want her to stay alone, she can't cook herself, since she doesn't have a fridge because of the noise. So, it takes a structure where there is really no noise: the fridge away. (P005)

In response to excessive noise, people living with ASDs sometimes adopt maladjusted strategies; isolation appears to be one of the most common. Other strategies are adaptations of activities and roles (person-environment interaction) to facilitate their success. For example, one participant reports that his child chooses his work schedule based on days when there is less noise.

Participants describe some elements of the environment as having a calming effect on their children, such as pale colours. For light, natural light was described as having a very positive effect, except for one participant who mentioned that natural light seemed to be disturbing for his child. One participant explained:

> Daylighting certainly makes a big difference. (...) We saw a big difference because in our old house (...), was very dark, and now we're in a condo with floor-to-ceiling windows; I saw a really big [positive] difference in behaviour. (P012)

However, too much light seemed disturbing for the children of all participants. A rotating light (a lamp that spins around itself and makes the light beams rotate) is described as calming and may promote sleep for some people with ASD.

The music seems to have a positive calming effect on several of the participants' children, and quiet and noise-free environments promote a sense of comfort.

Olfactory and tactile stimuli

Although they are less prominent in the results, four participants mentioned that certain olfactory stimuli (e.g., strong food odours when cooking) have a negative effect on their children. Related to tactile stimuli, soft textures seem to have a positive effect, while rough or pungent textures seem to have a disturbing effect (e.g., food, fabrics).

Finally, some proprioceptive stimuli, such as pressure on the body, seem to have a calming effect:

> I use a lizard (Manimo weighted stuffed lizard) that weighs twelve pounds to calm him down. When we see that he is anxious at home, (...) I put it on his shoulders (...) It's a weighing (...). It's calming. It's a bit like the big coat that weighs a lot. There is one in the house: he takes shelter with it. (P010)

Regarding nature, four participants describe it as a calming place for their children, even promoting communication.

> We did a lot of *canoe-camping* in northern Quebec (...), you're not full of stimuli, I found it was a completely different person. The calmer it is, the more they are in nature, the more they can focus on a beautiful communication, an exchange, not a monologue. (P012)

Coherence and safety in the non-human environment

Participants granted particular importance to the coherence of the elements integrated in an environment. For example, a panel that is not the same colour as the wall can be disturbing. Some environments seem to promote some activities; for example, the arrangement of furniture that creates a feeling of being surrounded can promote sleep. Storage space and filing systems seem significant for people living with ASDs. Each person seems to have their own different, consistent filing systems. Visual cueing of objects seems to help them. One participant explained that about his daughter. "It's really all filed, (...) she

knows where she puts her stuff, I don't do her housework anymore, because there was a fight about that. She has a place for everything" (P011).

Still related to coherence, stability (absence of change) in the non-human environment was emphasized by participants. Anxiety can arise when the environment presents changes or elements that are beyond the person's control.

> She doesn't want things to be moved around, she doesn't like to change the furniture, the decoration, the painting (...). We must keep the colour codes. If you want to paint so that she doesn't cry, you put the same colour back on. (P009)

The issue of safety is often raised by participants. Sharp, electrical, hot, or broken items can be dangerous for people living with ASDs. For example, some participants explained that broken items are disruptive, and their children will sometimes damage them even more by trying to remove what is already broken. Several participants noted that anything can become dangerous and highlighted the importance of safe environments: "When I say she is self-harming, she is much less sensitive to pain than we are, so she can stick a pencil or fork in herself; [if she is] in crisis, anything can become dangerous to her." (P003)

According to participants, under certain circumstances, these individuals may act abruptly:

> In our house, it is a marble countertop and then the sink is glued underneath. He leans so hard when he washes that he took off the sink; when we realized that it was leaking under the sink, my boyfriend says "yes, it wasn't done "*autistic-proof*". It takes solid but effective things. (P012)

The use of resistant materials would be adequate for the environment of people living with ASD, while still being comfortable.

Sometimes people living with ASDs may engage in risky behaviours, putting themselves or others at risk. Some risk behaviours are self-harm (e.g., related to sensation-seeking and hyposensitivity to pain) or destruction of the environment when disturbing elements are presented (e.g., broken clothing, pictures, or

items). One participant reported: “She likes to brush her hair a lot, she’ll even tear it out.” (P003). Participants identify adaptations to the non-human environment to alleviate safety-related difficulties. Another participant mentioned: “The whole house is adapted. We have no choice. And when I adapted, it’s not because it’s sophisticated, it’s mostly it’s safe all the way through.” (P004)

HUMAN ENVIRONMENT

The elements identified under this theme are the stability of the human environment, communication and technology.

Stability of the human environment

Regarding the stability and predictability of the human environment, most participants agree on the importance of routines and schedules for their children. Routines seem to support the functioning of people living with ASDs and changes become problematic, which can cause anxiety. One participant report “My son, just that I’m 5 minutes late, it can provoke a lot, a lot of anger to him.” (P006).

People living with ASDs often require adjustment from their human environment or need verbal or physical support to carry out their activities and roles. Several participants explained that they must constantly adjust to the needs of their children in terms of routines and schedules. One participant explained: “You shouldn’t rush him at any time, you really must adapt to his speed, his routine. At the end of the day, in our case, we live for him. We adapt to his time, his speed, his routine.” (P010)

Sometimes people living with ASDs can adopt maladjusted strategies when exposed to stimuli that are negative for them. On one hand, they may isolate themselves when there are many people or strangers, or in emotionally complex situations (e.g., conflict). Also related to the stability of the environment, participants in all focus groups spoke of visitors as being very disruptive to their children living with ASD, especially if the visit was not planned. Similarly, strangers can become an anxiety-provoking element. One participant said: “She doesn’t like visitors in the house, except for her sister. But there are people in

the family, like her grandparents, she says she feels they disturb her routine." (P009)

On the other hand, having a trusted person seems to be helpful for people living with ASDs. It allows them to confide in someone and to ask for help or support when needed, promoting a sense of security. According to participants, this role is often assumed by one of the parents, if the person lives in the family home.

Communication and technology

Participants discussed their children's relationships. Participants perceive relationships with other people with ASDs (homogeneity with the human environment) to be easier than with other people, such as neurotypical people or people with intellectual disabilities. Some indicate that in a residential setting, a place exclusive to people with ASDs must be favoured.

> You don't mix person with autism with a person with an intellectual disability. My son has a girlfriend that's been three years old, (...) she's intellectually disabled. (...) When she's tired, instead of saying, "Well, leave me alone," she says, "Not friends anymore, I don't love you anymore, go away, you're getting on my nerves...". And he, well, he's having an epileptic seizure. (...) The trick here is to put autistic people with autistic people, that's the winning formula. (P006)

Another element described as disruptive is the judgment towards people living with ASDs. Sometimes aggression may appear in situations where the person does not feel understood by those around him or her. As one participant said:

> I think it's important that people have a good perception of the phenomenon rather than categorizing it as a disease that needs to be cured. There is no cure for autism. You are autistic, you live with autism and you die with autism. (P014)

Finally, technology, such as a cell phone or computer, appears to be a supportive and positive communication element for some people living with ASDs, often used

as an adaptive strategy to avoid interactions. However, many participants identify difficulties in their children when communicating by telephone:

> She prefers in person or online [rather than on the phone]. Through *chat* or networks, Facebook, whatever, she's perfectly at ease. (...) She doesn't even want to make the appointment over the phone. She says, "Mom, I don't know what to say! If the person asks me questions, I get confused, I have too much stuff in my head at the same time, I'm not able to structure what I have to say." (P014)

On a different stream of thought, participants explained that elements such as acceptance of ASDs, coping skills, expectations, repetitive or stereotypical behaviours, hypo- and hypersensitivity, or digestive disorders also appear to have an impact on the activities and roles of people living with ASDs.

Overall, the results showed that elements are perceived as having a positive (Table 3) or negative (Table 4) effect on people living with ASD, depending on the type of stimuli and the individual's preferences. Thus, the impact of the same item may have a different effect on different individuals. These tables are not intended to establish causal links, but rather to provide examples of items that parents perceive to have an impact on the lives of their children living with an ASD.

Table 3. Examples of environmental elements perceived to have a positive effect on people living with ASD. (a) Non-human environment.

Element (what)			**Effect (how)**
Visual	Colour	Pales	Calm
Visual	Light	Natural	Calm
Visual		Rotating	Favouring sleep
Auditive	Music		Calm
Proprioceptive	Weighing	Soothing	Positive, but no effect has been described
Proprioceptive	Compression garments		Positive, but no effect has been described

Element (what)		Effect (how)
Storage space	Customized filing systems	Favouring competency situation
Storage space	Visual cueing of objects	Favouring competency situation
Resistant materials		Favouring competency situation
Stability		Sense of security, comfort
Cleanliness	Clean environment	Comfort
Object / personal space		Positive, but no effect has been described
Nature		Calm, encouraging communication

Table 3. Examples of environmental elements perceived to have a positive effect on people living with ASD. (b) Human environment.

Element (what)		Effect (how)
Homogeneity	People living with ASD	Encouraging communication
Judgments	Feeling understood	Positive, but no effect has been described
Trusted Person		Sense of security, request for support
Communication	Technology	Competence situation, favouring communication
Stability	Routine	Favouring the competency situation

Table 4. Examples of environmental elements perceived to have a negative effect on people living with ASD. (a) Non-human environment.

Element (what)			Effect (how)
Visual	Colour	Bright	Sleep disturbance, fatigue
Visual	Light	Excess light	Negative, but no effect has been described
Visual	Shape and pattern	Mosaic	Overcharge

Element (what)			Effect (how)
Visual	Congested environment		Fatigue, over-stimulation, anxiety
Auditive	Noise	Appliances	Anxiety, handicap situation
Auditive	Noise	Alarm, screams	Anxiety, discomfort, isolation
Olfactory	Strong smells (kitchen)		Negative, but no effect has been described
Tactile	Texture	Viscous (Food)	Handicap situation
Tactile	Texture	Rough (Textile)	Negative, but no effect has been described
Sharp, hot objects, electrical			Injury/self-injury
Broken elements			Discomfort, destructive behaviour
Changes			Anxiety
Cleanliness	Germs		Anxiety
Decorative elements			Over-stimulation

Table 4. Examples of environmental elements perceived to have a negative effect on people living with ASD. (b) Human environment.

Element (what)		Effect (how)
Heterogeneity	*Neurotypical* persons, other disabilities	Negative, but no effect has been described
Judgments	Feeling of incomprehension	Anxiety, aggressiveness
Judgments	Ignorance of ASD	Negative, but no effect has been described
Too many people		Anxiety, isolation
Visit	Planned	Discomfort
Visit	Not foreseen	Discomfort / Anxiety
Unknown		Anxiety, isolation
Communication	Emotionally complex situation	Isolation
Communication	Phone	Anxiety, handicap situation
Stability	Changes	Anxiety, inappropriate strategies

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Discussion

The purpose of this study was to explore the elements of the environment that affect the relationship between the person living with an ASD and his or her environment and the effect that these elements may have on the person. Many elements of the environment were identified by participants as having an impact on the activities and roles of their children living with ASDs that persist into adulthood. These elements and their impact, however, vary from person to person, meaning that the same element of the environment may have a different impact on each person or even the opposite effect. Thus, environmental interventions become a challenge, especially in an environment shared by several people, such as the living, working, and school environment. This challenge is related to the heterogeneity of ASDs profiles. Individuals living with ASDs may present a variety of manifestations in terms of their nature, severity, and progression (American Psychiatric Association, 2015; Charman, 2014; Fountain et al., 2012; Nazeer & Ghaziuddin, 2012).

This heterogeneity of manifestations related to ASD, as demonstrated in our results, is more related to the non-human environment, particularly for sensory elements. The idiosyncratic nature of environmental preferences is present in all persons, however, this appears to be more accentuated in people with ASDs (American Psychiatric Association, 2015). However, despite this heterogeneity, some elements that emerged in our results seem to be repeated in a larger number of people with ASD. These elements are noise, visual stimuli, safety, environmental stability, and control.

In our results, we found that one of the most common elements was noise, which could cause, according to the participants, discomfort, anxiety or even disability. These results are in line with the work of Landon and his collaborators (2016). Several types of noise were mentioned by the participants in our study as disturbing: noise from household appliances, continuous noise (e.g. machinery) and sudden noise (e.g. car alarm). Kanakri et al. (2017) also identified several types of potentially disturbing noises, including air conditioning and traffic noise, which are similar to those identified by our participants. Other authors like

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Arnaiz-Sánchez and colleagues (2011) and Mostafa (2008), identify noise as one of the elements to be considered in the design of environments for individuals with ASD because of the influence it can have on this population.

Regarding visual stimuli, we mainly found elements related to the lights and the colours in this study. Participants explained that natural light could be pleasant for their children and have a positive effect on their behaviour, conversely, to too much artificial light which could have a disturbing effect. Again, this goes in the same stream of thought as other studies that have also identified the excess of light as an element that can disturb people living with ASD (Pfeiffer et al., 2017; Stewart et al., 2016). For colours, our participants mentioned that their children tend to prefer pale or pastel colours over brighter colours which could be disruptive. Grandgeorge and Masataka (2016) suggest similar results in their study: children living with ASD had a preference for green and brown colours and the least preferred colour is yellow because it has a higher brightness value.

Concerning safety, we found that hyperreactivity to pain and temperature related to sensation-seeking may lead the person to use some objects to stimulate or even injure themselves. However, Richards et al. (2012) demonstrate that persons living with ASD and self-injurious behaviours had higher levels of hyperactivity and impulsivity and lower capacity to express themselves. Also, some people's awareness of danger is affected and may compromise their safety. As a result, sharp, electrical or hot items can put people at risk. Our results are consistent with those reported by Boyle et al. (2014), which describe the safety of children with ASD as a major concern for their parents.

The notion of stability is present in our findings both in the human and non-human environment, consistent with some characteristics that are common in people living with ASDs. According to Poljac et al. (2017), one of these characteristics seems to be their low adaptive capacity. This characteristic can be translated in having limitations in tolerating change and instability in the environment (human and non-human) and may interfere with person-environment interaction. According to the Model of Competence (Rousseau, 2017; Rousseau et al., 2002), the person is considered as an open system. The person and the environment are in constant interaction and there is a mutual

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influence between them. A low adaptive capacity can therefore disrupt this interaction and, consequently, the competence of developing activities and assuming roles. The home is, in principle, a safe and stable environment, unlike others such as school or public spaces, so it is worth noting that elements such as security and stability emerged in our results. This can lead us to reflect on and imagine of the significant proportions, in terms of stability and security, of the other environments in which an autistic person interacts.

The notion of control also seems to be present in this population. Many of the elements discussed in our study suggest that situations beyond the control of the person living with ASD may be problematic. Some of these elements include changes in plans, routines or schedules, unannounced visits, changes in decor, layout, or storage space. These are generally described as having negative effects on the person living with an ASD.

Our results indicate that in some situations, it is not just the environmental stimuli that disrupt activities and roles, but rather stimuli combined with the typical characteristics of ASD. Pfeiffer et al. (2017) report similar findings in their study of the environment of young children with ASDs. For example, regarding the interpretation of the information provided by the environment, adults living with ASDs appear to have a limited ability to select this information and distinguish between what is most and least important. Therefore, when the non-human environment presents many stimuli simultaneously, the person may experience fatigue or a behavioural crisis. Regarding the human environment, an emotional overloading situation may be difficult to manage due to low social skills, thus, the person may tend to isolate.

Strengths and Limitations

The results obtained in this study represent the parents' perceptions of the impact of the environment on their children living with ASDs. There is a limitation associated with the choice of the design research, and the results cannot replace a standardized assessment of the environment of people living with ASDs.

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Some strengths of the study support its credibility. On the one hand, the data were validated with the participants at the end of each focus group meeting, in accordance with this technique (Krueger & Casey, 2015). On the other hand, all the analyses were carried out by the research team and authors of this paper, to ensure rigour and minimize the bias associated with concordance during coding validation extracts done separately by two of the authors. The choice of moderator was also a strength of the study, due to his experience in group facilitation and his neutral role in the study (he is not a co-author of this article), thus minimizing the risk of bias during data collection. The validation of the coding was carried out on text extracts done separately by two of the authors and in agreement.

The main limitation concerns the transferability of the data; due to the diversity of the study population, a larger sample would have favoured transferability. Another limitation is related to coding validation (agreement=73%). This limitation is related to the structure of the code list which includes general codes that encompass specific codes. Also, this limitation is related to the difference in expertise between the two co-authors who performed the coding validation (occupational therapy and design) and the length of the text chosen for validation. A longer text could have resulted in a better percentage of agreement. This potential bias was minimized by including the four authors during the entire analysis process.

Conclusions

The identification of elements of the environment and their effects provides a better understanding of the interaction between the persons living with ASD and their environment, both human and non-human. The elements of the environment that have an impact on people with ASD are very heterogeneous, but several elements, such as sensory stimuli or changes in the environment, are recurrent. As mentioned before, the home environment is of vital importance for every individual. It is of most relevance the understanding of the feelings attached to this particular space, such as security and control, for the autistic person to live fully. Therefore, professionals involved in adapting the home

environment for people with ASD (e.g. occupational therapists) should assess the interaction between the person and his or her environment to identify the appropriate environmental elements and features for each person. The results of this study can guide professionals in their interventions with this population. However, more research needs to be done in order to better understand the person-environment interaction in the living environment and to provide tools for professionals.

Acknowledgments

The authors would like to thank the Office des personnes handicapées du Québec for funding the study (grant #N/D2231) and the Faculty of Medicine and the School of Rehabilitation of Université de Montréal for the scholarships awarded to the first author of the article.

Conflict of Interest

The authors have no conflicts of interest in connection with this study.

References

[1] American Psychiatric Association. (2015). *DSM-5 : manuel diagnostique et statistique des troubles mentaux* (J. D. Guelfi & M.-A. Crocq, Trans.; 5th ed.). Issy-les-Moulineaux : Elsevier Masson.

[2] Arnaiz Sánchez, P., Segado Vázquez, F., & Albaladejo Serrano, L. (2011). Autism and the Built Environment. In Intech (Ed.), *Autism Spectrum Disorders - From Genes to Environment* (pp. 364-380). Intech.

[3] Autism Spectrum Disorders in the European Union (ASDEU). (2018). *Executive summary 12/09/2018*. http://asdeu.eu/wp-content/uploads/2016/12/ASDEUExecSummary27September2018.pdf

[4] Autisme Quebec. (2019). *L'autisme en chiffres*. http://www.autisme.qc.ca/tsa/lautisme-en-chiffres.html

[5] Boyle, P., Haines, D., Lovelock, L., & Innes, K. (2014). Home Safety for Children with Autistic Spectrum Disorder: Local Authority Occupational Therapy

Intervention. *British Journal of Occupational Therapy*, *77*(5), 243-250. https://doi.org/10.4276/030802214x13990455043485

[6] British Medical Association. (2021). *Autism spectrum disorder*. Retrieved 19/04/2021 from https://www.bma.org.uk/what-we-do/population-health/child-health/autism-spectrum-disorder

[7] Brown, N. B., & Dunn, W. (2010). Relationship between context and sensory processing in children with autism. *American Journal of Occupational Therapy*, *64*(3), 474-483. https://doi.org/10.5014/ajot.2010.09077

[8] Charman, T. (2014). Variability in neurodevelopmental disorders. Evidence from Autism Spectrum Disorders. In J. V. Herwegen & D. Riby (Eds.), *Neurodevelopmental Disorders. Research challenges and solutions* (pp. 117-140). Psychology Press.

[9] Creswell, J. W. (2014). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (4 ed.). SAGE Publications.

[10] Elsabbagh, M., Divan, G., Koh, Y.-J., Kim, Y. S., Kauchali, S., Marcín, C., Montiel-Nava, C., Patel, V., Paula, C. S., Wang, C., Yasamy, M. T., & Fombonne, E. (2012). Global Prevalence of Autism and Other Pervasive Developmental Disorders. *5*(3), 160-179. https://doi.org/https://doi.org/10.1002/aur.239

[11] Fombonne, E. (2003). Epidemiological Surveys of Autism and Other Pervasive Developmental Disorders: An Update. *Journal of Autism and Developmental Disorders*, *33*(4), 365-382. https://doi.org/10.1023/a:1025054610557

[12] Fortin, M.-F., & Gagnon, J. (2016). *Fondements et étapes du processus de recherche : Méthodes quantitatives et qualitatives* (3 ed.). Chenelière Éducation.

[13] Fountain, C., Winter, A. S., & Bearman, P. S. (2012). Six developmental trajectories characterize children with autism. *Pediatrics*, *129*(5), e1112-1120. https://doi.org/10.1542/peds.2011-1601

[14] Gouvernement du Canada. (2018). *Trouble du Spectre De L'autisme chez les enfants et les adolescents au Canada 2018*. https://www.canada.ca/fr/sante-publique/services/publications/maladies-et-affections/trouble-spectre-autisme-enfants-adolescents-canada-2018.html#a2-2

[15] Grandgeorge, M., & Masataka, N. (2016). Atypical Color Preference in Children with Autism Spectrum Disorder. *Frontiers in Psychology*, *7*, 1-5, Article 1976. https://doi.org/10.3389/fpsyg.2016.01976

[16] Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *The Canadian Journal of Psychiatry*, *57*(5), 275–283.

[17] Kanakri, S. M., Shepley, M., Varni, J. W., & Tassinary, L. G. (2017). Noise and autism spectrum disorder in children: An exploratory survey. *Research in Developmental Disabilities*, *63*, 85-94. https://doi.org/10.1016/j.ridd.2017.02.004

[18] Kirby, A. V., Boyd, B. A., Williams, K. L., Faldowski, R. A., & Baranek, G. T. (2017). Sensory and repetitive behaviors among children with autism spectrum disorder at home. *Autism*, *21*(2), 142-154. https://doi.org/10.1177/1362361316632710

[19] Krueger, R. A., & Casey, M. A. (2015). *Focus Groups : A Practical Guide for Applied Research* (5th ed.). SAGE

[20] Landon, J., Shepherd, D., & Lodhia, V. (2016). A qualitative study of noise sensitivity in adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *32*, 43-52. https://doi.org/10.1016/j.rasd.2016.08.005

[21] Ludlow, A. K., & Wilkins, A. J. (2009). Case report: Color as a therapeutic intervention. *Journal of Autism and Developmental Disorders*, *39*(5), 815-818. https://doi.org/10.1007/s10803-008-0672-5

[22] Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research*, *11*(8), 1138-1147. https://doi.org/10.1002/aur.1965

[23] McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the Validity of a Quality of Life Measure for Autistic People. *Journal of Autism and Developmental Disorders*, *48*(5), 1596-1611. https://doi.org/10.1007/s10803-017-3402-z

[24] Miles, M. B., Huberman, M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). SAGE. https://us.sagepub.com/en-us/nam/qualitative-data-analysis/book239534

[25] Mostafa, M. (2008). An architecture for autism: concepts of design intervention for the autistic user. *ArchNet - IJAR: International journal of architectural research*, *2*(1), 189-211. http://search.ebscohost.com/login.aspx?direct=true&db=bvh&AN=612560&lang=fr&site=ehost-live

[26] Mostafa, M. (2014). Architecture for autism: autism ASPECTSS (TM) in school design. *ArchNet - IJAR: International journal of architectural research*, *8*(1),

143-158. http://search.ebscohost.com/login.aspx?direct=true&db=bvh&AN=713892&lang=fr&site=ehost-live

[27] Mostafa, M. (2015). Architecture for autism: Built environment performance in accordance to the autism ASPECTSSS design index. *Design Principles and Practices: An International Journal 8*.

[28] Nazeer, A., & Ghaziuddin, M. (2012). Autism spectrum disorders: clinical features and diagnosis. *Pediatr Clin North Am*, *59*(1), 19-25. https://doi.org/10.1016/j.pcl.2011.10.007

[29] Organisation Mondiale de la Santé. (2019). *Datos y cifras. Transtorno del espectro autista.* https://www.who.int/es/news-room/fact-sheets/detail/autism-spectrum-disorders

[30] Pfeiffer, B., Coster, W., Snethen, G., Derstine, M., Piller, A., & Tucker, C. (2017). Caregivers' Perspectives on the Sensory Environment and Participation in Daily Activities of Children With Autism Spectrum Disorder. *American Journal of Occupational Therapy*, *71*(4). https://doi.org/10.5014/ajot.2017.021360

[31] Pfeiffer, B., Kinnealey, M., Reed, C., & Herzberg, G. (2005). Sensory Modulation and Affective Disorders in Children and Adolescents With Asperger's Disorder. *American Journal of Occupational Therapy*, *59*(3), 335-345.

[32] Poljac, E., Hoofs, V., Princen, M. M., & Poljac, E. (2017). Understanding Behavioural Rigidity in Autism Spectrum Conditions: The Role of Intentional Control. *Journal of Autism and Developmental Disorders*, *47*(3), 714-727. https://doi.org/10.1007/s10803-016-3010-3

[33] QSR International. (2018). *NVivo*. In (Version 12)

[34] Richards, C., Oliver, C., Nelson, L., & Moss, J. (2012). Self-injurious behaviour in individuals with autism spectrum disorder and intellectual disability. *Journal of Intellectual Disability Research*, *56*(5), 476-489. https://doi.org/doi:10.1111/j.1365-2788.2012.01537.x

[35] Rousseau, J. (2017). Modèles généraux en ergothérapie: Le Modèle de compétence. In M.-C. Morel-Bracq (Ed.), *Les modèles conceptuels en ergothérapie-Introduction aux concepts fondamentaux* (2 ed., pp. 107-119). De Boeck Supérieur.

[36] Rousseau, J., Potvin, L., Dutil, E., & Falta, P. (2002). Model of Competence: A Conceptual Framework for Understanding the Person-Environment Interaction

for Persons with Motor Disabilities. *Occupational Therapy in Health Care*, *16*(1), 15-36. https://doi.org/doi:10.1080/J003v16n01_02

[37] Stewart, C. R., Sanchez, S. S., Grenesko, E. L., Brown, C. M., Chen, C. P., Keehn, B., Velasquez, F., Lincoln, A. J., & Muller, R. A. (2016). Sensory Symptoms and Processing of Nonverbal Auditory and Visual Stimuli in Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *46*(5), 1590-1601. https://doi.org/10.1007/s10803-015-2367-z

[38] Stewart, D. W., & Shamdasani, P. N. (1990). *Focus Group. Theory and Practice* (Vol. 20). SAGE Publications.

[39] Thorne, S. E. (2016). *Interpretive description : qualitative research for applied practice* (2 ed.). Routledge - Taylor & Francis. http://public.eblib.com/choice/publicfullrecord.aspx?p=4511832

Journal of Accessibility and Design for All

Volume 13, Issue 1. (CC) JACCES, 2023. ISSN: 2013-7087

How to cite this article:

Ruiz-Rodrigo, A., Morales, E., Louis-Delsoin, C., & Rousseau, J.. Parents' perceptions of the impact of the home environment on youth living with an Autism Spectrum Disorder. Journal of Accessibility and Design for All, 13(1), 43-68. https://doi.org/10.17411/jacces.v13i1.345

The Journal of Accessibility and Design for All, ISSN 2013-7087, is published by the Universitat Politècnica de Catalunya, Barcelona Tech, with the sponsoring of Fundación ONCE. This issue is free of charge and is available in electronic format.

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