TOWARD A THERAPEUTIC AND AUTISM-FRIENDLY HOME ENVIRONMENT

By WASAN NAGIB, B.SC.

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AUTHOR: Wasan Nagib, B.SC. (United Arab Emirates University)

SUPERVISOR: Dr. Allison M.Williams

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ABSTRACT

The unique characteristics of people with autism influence their spatial experience and interaction with the physical environment resulting in struggles not only to them but also to their families and caregivers. This research, which drew on the therapeutic landscapes theory, aimed at exploring these challenges in home environment and the role of modifying the physical home environment in alleviating these challenges. The research employed qualitative methods on three phases: a) learning from the experience of key informants who are involved in creating or modifying the home environment of people with autism. This phase involved interviews (n=4) with architects and interviews (n=2) and a focus group (n= 9 participants) with Occupational Therapists OTs) ; b) online survey across Canada and U.S.A with families of children with autism (n=168) , and; c) in-depth diary interviews with three selected case studies of families having children with autism and living in different housing typology (house, townhouse and apartment) in the Great Toronto Area. The identified themes provided comprehensive understanding on the following: (1) the common characteristics of people with autism affecting their interaction with the built environment; (2) the physical, social and psychological challenges that affect the quality of life of children with autism and their families in their home environment and the physical elements contributing to these challenges; (3) the common home modifications adapted by families to face these challenges; and; (4) the role of home modifications in shaping home environment as a therapeutic landscapes of healing. It was evident that the implemented modifications positively affected the families' experiences of home as a physical, social, and; symbolic space.

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PERSONAL STATEMENT

This thesis includes the stories of many families, who found autism suddenly becoming part of their lives. Before telling their stories, I would like to begin with my own personal story with autism while reflecting on my journey in writing this thesis.

After graduating from architecture school, my first goal was to seek a professional career as an architect. I spent two years practicing design, particularly for homes, in one of the top consultant firms in the United Arab Emirates (UAE). At the time, this experience provided me with tremendous experience, not only in design but with how to best meet the expectations of clients' many different tastes. I was ready for even more until I realized that there was something wrong with one of my two and a half -year-old twins. When I started thinking about it deeply, looking back and comparing him with his twin brother, I immediately noticed the connection; he was late in everything he attempted, whether crawling, walking or talking.

I quickly learned two things: first, schools in UAE start accepting children at the age of three. Second, that the child's brain stops developing after the age of six. I knew I had very limited time if I wanted him to join school with his peers, particularly his twin brother. And that's when my life changed dramatically.

I quit my job and started taking him to different centers specializing in children's developmental disorders. I spent days and nights reading about autism and would not hesitate to implement any recommended plan that might help him. I would attend all his therapy sessions and learn from the therapists in order to apply their strategies beyond the session

time. I would also read about nutrition and apply the dietary recommendations that research proved might help in increasing attention span which is essential in learning anything.

One thing I did do that had an almost immediate effect was when I applied some of the physical modifications i had learned in architecture to the room where I was teaching him. I noticed he was more responsive than before the changes were made. For example, setting the study table in a quiet area away from sources of distraction, which in his case was the window. Another thing was avoiding cluttering of furniture and toys, and minimizing colors on the walls. With continuous effort, my son started progressing fast. I am now proud to say that now he is in grade 3 in a mainstream school just like his twin brother.

This experience didn't just make me stronger as a mother, but it also opened my eyes to a totally new world. In architecture, we learn how to design but we were never taught to think about how people 'feel' or react toward these designs. Now I truly believe that space is not only occupational but also 'therapeutic', contributing to our healing.

With a great passion to fill this gap in architecture, I joined the School of Geography and Earth Sciences at McMaster University. Throughout my two year journey involved in this study, I can now say that the meaning of 'space' to me has changed completely when compared to when I was an architect.

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CHAPTER 1

INTRODUCTION

1.1 Background and Research Rationale

My research interest lies in the broad area of environment and health. I am particularly interested in developing therapeutic built environments for children with Autism Spectrum Disorder (ASD). The significance of this research stems from the fact that autism is by far the most rapidly advancing childhood disorder in North America. A recent study (Baio et al 2012) indicated that autism now affects 1 in 88 children and 1 in 54 boys in the USA. Whether these numbers signify an "epidemic", or an "epidemic of discovery" (Ginker 2007), can be debated, but what is not really debatable is that the increase in autism incidence is very large. Autism has become part of our developmental landscape.

Ninety-five of children with autism demonstrate some sensory processing dysfunction, including sensation seeking, auditory filtering and tactile sensitivity (Tomcheck and Dunn 2007). These problems affect the way in which they interact with and process the demands of their environment, often resulting in restless or disruptive behavior, tantrums, and a limited attention span (Barker-Dunbar 1998, Admason et el 2006). Thus, by analyzing the context, we may better understand the motivation behind problem behavior. Research findings in the field of autism and environment have induced a growing stream of research which aims at exploring

how to develop a *therapeutic* context, an approach that explores the healing effects of the environment and the importance of place to physical and mental wellbeing (Williams 2007).

1.2 Research Problem

Despite its overwhelming incidence, designing for autism is highly ignored and excluded from building codes and guidelines, even those developed specifically for special needs individuals. Architect Magda Mostafa (2008) interviewed a technical staff member of the *International Code Council*, who stated: "*I know of no building or accessibility code that incorporates requirements specifically to address children with autism."* (P. 143).

In a recent article in the electronic journal, *Disability Studies Quarterly,* Robertson (2010) argues that "living in a society designed for non-autistic people contributes to, and exacerbates, many of the daily living challenges that autistic people experience." Another study reported that 40% of mothers judged their home to be 'unsuitable' to accommodate the needs of their children with autism (Bromley et al 2004). Trained as a professional architect and being a mother of a child with autism, I continuously noticed that modifying the physical environment to meet his needs had an impact on improving his skills and keeping him motivated. These modifications were also valued as an occupational, personal and emotional necessity for my family.

Therefore, there is an urgent need to rethink the way we design our everyday places. Focusing on the home environment will not only help in the healing process of our children with autism, but will also improve the quality of life of the whole family.

1.3 Research Questions and Objectives

Using the therapeutic landscape theory (Williams 2007), my research aims at providing answers to the following questions:

1. *Using **Therapeutic Landscape theory**, what are the physical, social and psychological challenges that affect the quality of life of children with autism and their families in their home environment?*

2. *How can the physical elements of the home environment be designed (or modified) to alleviate these challenges and create an autism-friendly home?*

The research aims at achieving a series of objectives, including:

1. Understanding the common characteristics of people with autism which affect their interaction with the built environment.

2. Understanding the common challenges of people with autism and their families in their home environment , as well as the physical elements contributing to these challenges.

3. Identifying the common home modifications adapted by families to face these challenges.

4. Exploring in detail the life experience of families and their quality of life before and after modifications.

1.4 Outline of Chapters

The following six chapters will begin with a review of current literature (Chapter 2) from architecture, occupational therapy and health geography, with a focus on autism and its characteristics, home design, physical modifications, therapeutic landscapes, and the meaning of home for families of children with autism.

In Chapter 3, I will be outlining information about the study's geographical context before moving on to discussing the research methods employed to collect data presented in this research. Chapter 4 aims to answer the research questions through the research three phases. The first phase included the perspectives of two professional groups (architects and occupational therapists) involved in creating autism-friendly environments. Further, survey data collection from families living with children with autism are presented in phase two. Phase three involved exploring the lived experience through interviews with three selected families of children with autism, one for each housing typology (1-detached; 2-townhouse, and 3-apartment) and how their quality of life was affected by adapting home modification. The main themes, specifically challenges and modifications that arouse from my interviews and survey with participants will be described.

The purpose of Chapter 5 is to compare the findings discussed in Chapter 4 and relate them to the literature, in addition to discussing how home modifications can help in shaping the home environment as a therapeutic landscape of healing.

Finally, in Chapter 6, I will sum up the findings and provide recommendations and directions for future research to hopefully create autism-friendly home environments that improves the quality of life not only of children with autism, but their families as well. Study contributions and limitations will be highlighted, followed by concluding thoughts.

CHAPTER 2

LITERATURE REVIEW

This study is situated at the intersection of several disciplines; architecture (concerning home design and physical modifications), occupation therapy (concerning autism behaviors, treatment, and related home modifications) and health geography (concerning therapeutic landscapes and the meaning of home for families with autism). This chapter provides an overview on related scholarly work in order to identify the dearth in the existing literature and place the study within the context of this research gap. Following an introduction on autism characteristics and prevalence, the impact of the physical environment on the functional and social performance, perception, and behavior of people with autism will then be discussed. Literature on the architectural design strategies for developing autism-friendly built environment will be explored. To focus on the home environment, literature on home modifications and their impact on the experience and meaning of home will be reviewed. Finally, the therapeutic landscapes approach will be discussed as a idealized framework to study the lived experience and meaning of home by families with children with autism.

2.1 Introduction to Autism

2.1.1 What is Autism?

Autism was first identified in 1943 by Dr. Leo Kanner of Johns Hopkins Hospital. It is a complex developmental disability that typically appears during the first three years of life. The

result of a neurological disorder that affects the functioning of the brain, autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. Autism is a spectrum disorder. The symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviors, children and adults can exhibit any combination of the behaviors in any degree of severity. Two children, both with the same diagnosis, can act very differently from one another and have varying skills.

2.1.2 Prevalence of Autism:

Autism is the most common of the childhood developmental disorders, affecting an estimated 2 to 6 per 1,000 individuals (Centers for Disease Control and Prevention, 2001). This means that as many as 1.5 million Americans and 50, 000 Canadians today are believed to have some form of autism. And that number is on the rise. Based on statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a rate of 10 to 17 percent per year. At these rates, the Autism Society of America (ASA) estimates that the prevalence of autism could reach 4 million Americans in the next decade. The overall incidence of autism is consistent around the globe, but is four times more prevalent in boys than girls. Autism knows no racial, ethnic, economic or social boundaries.

2.1.3 What Causes Autism?

There is no single known cause for autism, but it is generally accepted that it is caused by abnormalities in brain structure or function. Brain scans show differences in the shape and structure of the brain in autistic versus non-autistic children. Researchers are investigating a number of theories, including the link between heredity, genetics and medical problems. In many families, there appears to be a pattern of autism or related disabilities, further supporting the theory of a genetic basis to the disorder.

While no one gene has been identified as causing autism, researchers are searching for irregular segments of genetic code that autistic children may have inherited. It also appears that some children are born with a susceptibility to autism, but researchers have not yet identified a single "trigger" that causes autism to develop. Whatever the cause, it is clear that children with autism are born with the disorder or born with the potential to develop it. It is not caused by bad parenting. Autism is not a mental illness. Children with autism are not unruly kids who choose not to behave. Furthermore, no known psychological factors in the development of the child have been shown to cause autism.

2.2 Autism and the Role of Context

Autism, like other behavior disorders, cannot be fully comprehended in isolation of its context. There is a little consensus on the definition of this context. However, in autism research, the word context is used to refer to pretty much any influence beyond inherited genes. The contextual variables cover a wide range of social, physical, environmental,

economic and political domains. The role of context has contributed extensively to shaping the current thinking and research on autism. In the following pages, three streams will be discussed, each with examples of related up-to-date empirical research on autism. The discussion will cover the role of context in: autism risk; stimulating autism behaviors, and; information processing.

2.2.1 The Role of Context in Autism Risk

This line of research attempts to investigate the factors behind the dramatic prevalence of autism. For the last two decades autism research has focused heavily on the possible genetic roots of the condition. It has been considered the most heritable (genetic) of neurodevelopment disorders (Linchtenstin 2010). However a recent study, the California Autism Twin Study (CATS), which was conducted in the Stanford School of Medicine, suggests that environmental (non-genetic) factors play an unexpectedly large role in determining autism risk (Hallmayer 2011). The study, which is the largest and most rigorous twin study ever conducted, represents a significant shift in scientists' understanding of the potential cause of autism. Drawing upon state records, the CATS researchers identified 192 pairs of twins in which at least one of the two had some form of autism. Among these sets, there were 54 pairs of identical and 138 pairs of fraternal twins. The study found that the likelihood of both twins being affected by autism was higher among identical than fraternal twins. This suggests that genetics plays a key role in the disorder. But importantly, the chance of both twins being affected by autism was not low among fraternal twins, which is counter to what would be expected if genetics were the dominant factor. Using mathematical formulas the study

estimated that the genes twins share can increase the risk of getting autism by almost 40%, while the contextual factors count for the other 60%. This is in contrast to prior research which estimated the environmental factors only accounted for only 10%. The study suggested that the genetic base, together with the environmental factors, may explain autism, and those contextual factors that occur in uteri, during childbirth or soon thereafter may trigger the susceptible genes. Such contextual factors that could influence a child developing autism might be parental age, low birth rates, multiple births or maternal infections during pregnancy.

Several studies have attempted to explore contextual risk factors related to autism. Volk et al, (2011) examined the association between autism and proximity of residence to freeways and major roadways during pregnancy and near the time of delivery, as a surrogate for traffic-related air pollution exposure. Data were from 304 autism cases and 259 typically developing controls (a child is considered typically developing it he is able to children acquire a wide range of skills similar to the majority of children of the same age within the same culture). The mother's address recorded on the birth certificate and trimester-specific addresses derived from a residential history obtained by questionnaire were geocoded, and measures of distance to freeways and major roads were calculated using GIS software. Logistic regression models compared residential proximity to freeways and major roads for autism cases and typically developing controls. The study found that living near a freeway during the third trimester of pregnancy and at the time of delivery was associated with autism. The study suggested that the larger volume of traffic and concentrations of pollutants observed near freeways induce inflammation and oxidative stress which is involved in the pathogenesis of autism. The study

also suggested that further research to examine of gene–pollution interactions may all help us learn about causal pathways involved in autism and identify potentially susceptible populations and may lead to prevention strategies. It has been estimated that 11% of the U.S. population lives within 100 m of a four-lane highway, so a causal link to autism or other neuro-developmental disorders would have broad public health implications.

Similar findings have been suggested by Windlam et al (2006), who linked the California autism surveillance system to the exposure to hazardous air pollutant concentrations compiled by the U.S. Environmental Protection Agency. Results of this semi ecologic study suggest that living in areas with higher ambient levels of air pollutants, particularly metals and chlorinated solvents, during pregnancy or early childhood, may be associated with a moderately increased risk of autism. The study suggested that more complex etiologic studies with measurements of individual level exposures to multiple compounds by various pathways (air, water, diet), combined with genetic information, will be important to further our understanding of the potential contribution of environmental exposures to the development of autism.

Gene-environment interaction has been addressed by a recent study by Thomas and Kaper (2012). The study investigated the relationship between the exposure to psychiatric medicines and the risk of autism. Concentrations of the drugs found downstream from water treatment plants that process human waste contains these medicines. The molecules make their way into the supply downstream, where pregnant mothers who drink the water can pass the exposure to their fetuses. Researchers put the anti-depressants Prozac and Effexor, as well as the anti-seizure drug, Tegratol, into water tanks of minnows. Tests showed that the same

genes turned on in people with autism were also triggered in the fish after exposure. The findings suggest that small amounts of psychiatric medications found in the drinking supply may contribute to the development of autism.

Callaway (2012) investigated the relationship between parental age and autism risk. the study analyzed genetic material taken from blood samples of 78 parent-child trios, focusing on families in which parents with no signs of a mental disorder gave birth to a child who developed autism or schizophrenia. This approach allows scientists to isolate brand-new mutations in the genes of the child that were not present in the parents. The research team found that the average child born to a 20-year-old father had 25 random mutations that could be traced to paternal genetic material. The number increased steadily by two mutations a year, reaching 65 mutations for offspring of 40-year-old men. The average number of mutations coming from the mother's side was 15, no matter her age. The study provided solid evidence that older men are more likely than young ones to father a child who develops autism because of random mutations that become more numerous with advancing paternal. The age of mothers had no bearing on the risk for autism.

2.2.2 The Role of Context in Stimulating and Motivating Autism Behavior

Many individuals with autism and sub-average intellectual ability exhibit serious problem behaviors, such as aggression, self-injury, property destruction, and tantrums. These behaviors have a profoundly negative impact on quality of life, not only for the person displaying the behavior but also for members of their family. Problem behavior limits

opportunities for community living, employment, school inclusion, and social relationships, as well as demoralizing family members, frightening teachers, and alienating peers (Koegel, Koegel, & Dunlap, 1996). For these reasons, much research has been devoted to understanding the motivation behind such behavior (an assessment issue) and linking treatments to motivation (an intervention issue).

According to Carr (2007), the purpose of problem behavior varies according to specific features of the context in which the behavior is displayed. Thus, by analyzing context, we may better understand the motivation behind problem behavior and be in a stronger position to design meaningful interventions. Carr (2007) hypothesized that problem behavior is related to two classes of contextual factors: discriminative stimuli and setting events. A discriminative stimulus is a discrete event that is likely to trigger the behavior. A setting event is a variable that influences ongoing (discriminative) stimulus-response relationships. Three major categories of context variables have been identified in the literature (Carr and Smith 1995): social, activities/routines, and biological. Social factors include variables such as communication difficulties, being denied access to desired items, and relationship problems. Activities/routines include factors related to task preferences (e.g., tasks that are difficult, boring, or too long), having to wait, changes in routines, and transitions. Biological factors include variables such as medication side effects, illness, and body states (McAtee, Carr, & Schulte, 2004). Analyzing these contextual variables may provide insight on the motivation behind problem behavior and the best way to deal with it.

2.2.3 The Role of Context in Information Processing

A growing number of researches are devoted to understanding how people with autism perceive their context. Children with autism perceive their world in a very different way. The filtering mechanism in their brains often works in a different way in assimilating the senses, such as touch, smell, hearing, taste and sight. They may be extremely sensitive to some senses and find seemingly routine events fascinating - the patterns of light on a wall, or the rustling leaves in the wind. The autistic child may also be unresponsive to sensations that their parents find unpleasant, such as extreme heat, cold or pain. Understanding how people with autism perceive the context is very crucial for designing proper intervention methods. (Vermeulen, 2011).

The following are some examples of research on sensory processing in autism. For example**,** Literature on visual perception in autism has convincingly demonstrated superior performance in tasks requiring recognition of details, ability to find hidden figures, and visual search in feature and conjunctive search tasks. By contrast, perception of dynamic and complex stimuli has been shown to be defective. Hypotheses explaining, such perceptual abnormalities include superior processing of low-level static information, and increased internal noise, potentially amplifying local differences and masking global differences (Simmons et al 2009). Becchio et al (2010) present an example of empirical research on visual perception. The study attempted to investigate whether individuals with autism can exploit the information conveyed by cast shadows and whether they are especially sensitive to noise aspects of shadows (A cast shadow is a type of shadow that is created on a form next to a surface that is turned away from

the source of light). The study concluded that shadow-processing mechanisms are abnormal in autism. As a result, processing shadows may interfere rather than help object recognition.

There is now a growing body of evidence that attests to unusual sensory processing as least concomitant and, possibly the cause of some of the behavioral signs and symptoms associated with autism. For example, people with autism respond to a lack or abundance of sensory input by flapping hands, shutting off certain senses, and doing other abnormal behaviors (Albano 2008). In addition, research also revealed that contextual sensitivity is crucial in exactly those areas known to be affected in autism: social interaction, communication, and flexibility in thoughts and behavior. This has led to the hypothesis of context blindness as the common pathway in the cognitive deficits in autism. Context blindness refers to a reduced spontaneous use of context when giving meaning to a stimulus. To put it more simply: the autistic brain thinks in an absolute way, rather than a relative, contextually defined way. For example, when the doorbell rang, the mother of a seven-year-old boy with autism asked him to open the door. He opened the back door instead of the front. His reaction was logical, but his choice of door was out of context.

The preceding discussion reveals the profound impact of physical environment on the functional and social performance, perception, behavior and, in turn, the quality of life on people with autism. It is therefore essential to prepare our built environment to accommodate their specific needs. The home environment is the foremost to be considered due to the powerful physical, psychological, emotional, and spiritual significance it has in our lives. As stated by Marshall (2008) in her research on home as place of healing “home provides the

optimal, essential, environment for healing" (p 263). This leads to a relatively new line of research conducted by architects, as will be demonstrated in the following section, which rethinks the built environment in light of autism.

2.3 Architecture for Autism:

In the past few decades, contemporary architecture started to consider the needs of individuals with different degrees of visual, hearing and motor disabilities. Architecture guidelines and standards have been developed to insure that indoor and outdoor spaces can be inhabited by these people. The keyword in architecture for disability is "accessibility", which is clearly a physical concept referring to enabling people with disabilities to access buildings and spaces. Research has addressed accessibility to: various types of buildings (Martins and Gaudiot 2012); urban spaces (Beale et al 2006); and, houses (Imrie 2006). Further, universal designs that are inherently accessible for people with or without disabilities have been developed (Iwarsson and Stahl 2003).

However, research related to architectural design for people with cognitive and sensory impairments, which are less visible, are limited (Mostafa 2008 and Khare and Mullick 2009). Among this group are people with autism. Due to their impairments, they are forced to make an effort to grasp and understand the environment around them, given their difficulty in processing information received through their senses (Sanchez, Vazquez and Serrano 2011). Many elements in the environment which other people ignore or block out, such as background noise, flickering light, or a bright color, can be very disturbing to people with autism. Such

elements can become a barrier toward understanding their environment and, in turn, may trigger anxiety, frustration, aggressiveness, tantrums and strange behaviors such as gestures or weird sounds or movements (Sanchez, Vazquez and Serrano 2011). As argued by Robertson (2010, online journal) *"Living in a society designed for non-autistic people contributes to, and exacerbates, many of the daily life challenges that autistic people experience*". There for, architects can play an important role in making our society more autism-friendly.

A number of architectural design strategies can facilitate creating autism-friendly built environments. It should be noted here that the majority of these research efforts have focused on the design of schools and learning environments.

Humphreys (2008) highlighted some simple architectural concepts which, if applied, can help architects in making autism-friendly designs. He drew on his experience in designing a school in Newcastle, United Kingdom. To reduce auditory and visual stimulation and assist people with autism in comprehending the space around them, Humphreys suggested the following principles: maintaining a sense of calm, order, and simplicity in building layout; providing a good level of natural lighting; providing good quality acoustics, and; minimizing details and materials.

To ensure security and safety for both people with autism and the surrounding environment Humphreys suggested the following principles:

1. Providing secured boundaries that allow freedom of movement within a contained environment;

2. The utilization of easily managed and durable materials to withstand possible aggressive behavior;
3. Providing well observed spaces to fulfill the need of supervision while avoiding unnecessary intrusion in the ongoing activities;

For the sake of improving social interaction Humphreys (2008) stressed the principles of "Proxemics", which refers to the personal space that people feel is necessary to set between them. Humphreys argued that people with autism usually need larger personal space to facilitate social interaction. This should be accounted for in the design of any space.

Magda Mostafa (2008) provided a unique evidence-based design strategy for an educational environment. In the first phase of her study, a questionnaire of primary caregivers was conducted to determine the most influential architectural elements impacting autistic behavior. The result revealed that acoustics were ranked as the most influential, followed by the spatial sequencing of functions (the sequence in which activities are distributed in the space). Lighting, colors, texture and olfactory were given less influential importance. In the second phase, an intervention study was conducted to test the impact of enhancing the top two elements on the performance of children with autism attending a specialized educational center in Cairo. Acoustical modifications involved sound proofing to reduce noise, while special sequencing was enhanced by organizing classroom activities into separate defined zones. The study tracked the performance, pre and post intervention, of a control and study group and concluded the positive outcome on increasing attention span, reducing response time and improving behavioral temperament of the students with autism.

Scott (2009) analyzed the designs of four newly built schools for children with autism in the UK by interviewing both the architects and educational staff. Based on the analysis, and out of his personal experience as a professional architect, Scott (2009) extracted the following design considerations for autism-friendly educational space:

1. To create an ordered and comprehensible spatial structure;
2. To generate a mix of small and large spaces;
3. To provide the users with more control over environmental conditions;
4. To accommodate different teaching strategies for purple with autism;
5. To achieve a balance between safety and independence;
6. To provide simple and reduced detailing;
7. To get the end-user actively involved in pre-design (defining the contents of the building) and design process;
8. To appropriately use technology to aid the learning experience of pupils with autism.

Vogel (2008) provided another interesting research study on the classroom environment. Instead of defining design criteria, she focused on addressing the qualities of a built environment for people with autism. According to Vogel (2008) the environment must be flexible / adaptable to accommodate different activities, non-threatening, non-distracting, predictable, controllable, sensory-motor attuned, safe, and non-institutional. These qualities provide a general framework within which architects may develop many design strategies, depending on the specific project at hand.

Khare and Mullick (2009) highlighted the following design parameters for creating 'universal' educational spaces which suit people either with or without autism:

1. Provide an organized environment with clear physical boundaries for each activity;
2. Provide visual cues such as color coding, signs, labels, pictures etc. to define the use of spaces;
3. Provide space for interaction with parents and the community within school environment;
4. Provide generous spatial standards to allow for a larger personal space for each child;
5. Provide a withdrawal space (also called the quit room) which is a quite space where the child can retire to avoid or mitigate the stress he may feel in certain moments;
6. Eliminate elements that could derive risks due to the pupils' misperception of danger;
7. Provide clear space arrangement, defined activity zones, and minimize cluttering;
8. Use durable materials, furniture, and equipments to minimize maintenance due to possible aggressive behaviors;
9. Minimize sensory distractive elements;
10. Allow for monitoring and supervision.

Beaver (2010) provided some of the rare literature which addresses the creation of a suitable residential environment for people with autism. He explained certain strategies which he applied in designing a residential-educational center. They can be summarized as follows:

1. Provide wide corridors that can be used also as play area to reserve living rooms for quieter activities;

2. Provide larger spatial standard to allow for more personal spaces;
3. Reduce noise by using carpet flooring and sound proofing;
4. Think about safety specially when designing bathrooms and kitchens. Fittings must be firmly fixed and pipes must not be exposed;
5. Use under floor heating or radiant ceiling panels and natural ventilation.
6. Place safety locks for windows and doors leading to outside;
7. Provide indirect and defused lighting and avoid traditional fluorescent lamps;
8. Provide “quiet rooms” where the child can calm after tantrum or when experiencing to much stress;
9. Provide “sensory rooms”, where the child can use multi-sensory experience to explore, to calm, and to practice important social skills. High-end sensory room is equipped with sensory equipments and activities to benefit specific sensory possessing difficulties. It should be tailored to one’s specific sensory needs.

Although most of the design strategies discussed above have been developed for classroom and educational environment, the ideas can be extrapolated to other environments including family homes (Vogel 2008). To conclude this section, Table (2.1) synthesizes the design strategies suggested with respect to each autism impairment.

Challenges	Architectural design strategy	Humphreys	Mostafa (2008)	Scott (2009)	Vogal (2008)	Khare & M.	Beaver (2006)
		Schools & learning Environment					Res.
Impairments in Imagination: (Resistance to change, sticking to routine, and limited ability to anticipate what comes next)	• Clear and simple building layout and space arrangement	■	■	■	■	■	
	• Use visual cues to define what is behind doors.		■			■	
	• Create intermediate (transition) spaces.						
	• Place activities and elements in order.		■				
Impairments in communication: (Difficulties in verbal & non-verbal communication and in information processing and easily to be distracted)	• Avoid cluttering		■		■		
	• Minimization of details	■	■	■			
	• Providing a separate zone for each activity		■				
	• Provide space for visual instruction (e.g. signs)		■				
	• Providing spaces for low and high-Tec communication devices.			■			
	• Provide space for therapy and training		■				
	• Use neutral background to avoid distraction						
Sensory dysfunction: (Difficulty in reception or processing of visual, auditory, factory or tactile stimuli in the form of hyper or hyposensitivity. Dysfunction in pain sensation)	• Provide quality aquatics to control noise	■	■		■		■
	• Provide defused, preferable natural lighting	■					■
	• Avoid traditional fluorescent tubes						■
	• Provide sensory rooms to appropriately experience sensory stimulation		■				■
	• Provide controlled heating and cooling systems.						■
	• Use soft colors and avoid contrast				■		
Impairments in social interaction: (Difficulty in understanding others feelings and emotions, in getting attention and in developing relationships. Social situations are overloading. Remain physically withdrawn from people	• Provide generous spatial standards to allow for more personal spaces	■	■			■	■
	• Provide “quite room” where the child can withdraw to calm after tantrum or excessive stress		■			■	■
	• Provide space for interaction with peers, parents and community in school environment					■	
	• Provide a mix of small and large spaces			■			
	• Provide wide corridors which can accommodate playing activities						■
Safety and behavior: (Misperception of danger, aggressive behavior, and abuse of physical elements and equipments)	• Provide secured physical boundaries to allow freedom of movement within a contained spaces	■		■	■	■	
	• Utilize durable materials to withstand possible abuse or aggressive behavior	■				■	
	• Provide will observed spaces to allow for supervision while minimizing unnecessary intrusion	■				■	
	• Provide locks for windows and external doors						■
	• Well fixation of elements and avoid sharp edges					■	
	• Provide special attention to safety in bathrooms and kitchens						■

Table (2.1) Summary of challenges and design strategies.

2.4 Home Modifications and the Meaning of Home

Home modification is a subject that attracts increasing attention in many fields, including occupational therapy, nursing, environmental psychology and health geography. Home modifications are defined as conversions or adaptations to the permanent physical features of the home environment to reduce the demands from the physical environment in order to make tasks easier; reduce accidents, and; support independent living (Fange &Iwarsson, 2005; Pynoos, 1993). Some literature expanded the definition behinds modifying physical elements to include behavioral change, the utilization of any special equipment, and any additional categories that family caregivers deemed important (Pynoos et al 1987 and Messecar el al 2002).

The recent trend in health care delivery which fosters transferring care from formal spaces, such as hospitals and institutions, toward informal settings, such as homes, increases the importance of home modification as a research topic. Leaving the responsibility for meeting patients' need in the hands of family caregivers requires, among other factors, a physical home environment that can be adapted to meet the patient's needs (Williams 2004).

A significant amount of literature related to home modifications has been directed to addressing the caregiving of elders and people with physical impairments (Messecar et al 2002, Tanner et al 2008, and Pysoon 1993, Paysoon et al 2003). Research findings suggest that such environmental interventions have decreased the difficulty and lowered the dependence on

others in performing household tasks for people with mobility impairment (Connell, Sanford, Long, Archea, &Turner, 1993). They have also improved the functional performance in areas of self care and instrumental activities of daily living for the frail elderly, people with dementia, and those with mild functional impairment (Giltin et al., 1999; Mann et al., 1999; Trickey et al., 1993), while reducing the need for and the effectiveness of caregivers (Gitlin et al., 2001; Lanspery, Callahan, Miller, & Hyde, 1997). Task performance, in terms of parameters such as independence, safety, and quality, has become the key way that researchers in the home modifications field have operationalized the concept of "person–environment fit" (Faletti, 1984; Steinfeld & Danford, 1999). However, home is much more than the physical environment. As pointed out by Tanner et al (2008), 'People and places are seen as engaged in a dynamic, reciprocal relationship through which home becomes a place of significant personal meaning'. Tanner et al (2008, p159) investigated the impact that home modifications have on the experienced meaning of home by older people living in the community. The study revealed positive impacts on supporting continuation of daily routine and social relationships at home, and therefore, contributing to a sense of comfort, control, and identity. The study also revealed a negative impact, when functionality is over emphasized, or when the home dweller has less of a role in decision-making processes around the modifications.

Despite the increasing interest in studying housing modifications, there has been little investigation of how home modifications affect the experience and meaning of home to both patients and their families (Williams 2002). This is particularly true in the case of mental or

developmental disabilities (including autism), where research remains remarkably underdeveloped (Evans et al 2003, Pengelly et al 2009).

Pengelly et al (2009) conducted one of the few investigations on the interrelationship between home modifications and the lived experience of three families with a child diagnosed with autism. Each family had acquired an extra downstairs room through moving or adapting their home, which they dedicated to their child with autism. Diary records and narrative interviews were used to gain in-depth understanding of how the room was used, the meaning that the families attach to this additional space and the impact that it had upon the family members. The study revealed the personal, emotional, and occupational importance of this space for the children with autism, and their families.

2.5 Therapeutic Landscapes

Health geography is a recent development of the 'reformed' medical geography, focusing on place-based dimensions of health. Health geographers are paying increasing attention to ways in which place relates to people's experience of health and health care (Chakrabarti 2010). One way to approach the place/health relationship is through therapeutic landscapes theory. The term 'therapeutic landscapes' was introduced by Gesler (1992, 1993), who defined therapeutic landscapes as locations associated with treatment or healing. They are places in which "Physical and built environment, social conditions and human perceptions combine to produce an atmosphere which is conducive to healing" (Gesler 1996). Williams

(1999) expanded the definition to include not only healing but also maintenance of health and well-being.

The theory of therapeutic landscapes has greatly enhanced understandings of health and place by uncovering the ways in which individual, social, cultural, environmental and structural factors interact in creating healing landscapes (Gesler 1992). Since the appearance of the theory of 'therapeutic landscapes', pioneered within health geography, its importance began to be recognized in other disciplines such as: nursing (Gilmour, 2006; Kennedy, Shannon, & Chuahorm, 2004), landscape and urban planning (Rodiek & Fried, 2005), and kinesiology (Goodwin & Staples,2005; Van Ingen, 2004). There has emerged a growing body of evidence to support the observation that landscapes can benefit health and wellbeing. Scanning through therapeutic landscape literature over the past 20 years reveals that the types of places associated with healing that have been addressed appear to fall under three main categories: places pertaining to extraordinary landscapes, places representing everyday landscapes of healing, and places of formal healthcare delivery (English et al. 2008). The term 'extraordinary' here refers to therapeutic landscapes located outside the realm of people's day-to-day life, and known to have enduring reputation for healing. Extraordinary therapeutic landscapes tend to involve encounters with distant locations and often associated with extraordinary events in people's lives (English et al 2008).

A significant amount of early literature is dedicated to analyzing the therapeutic landscapes of extraordinary places. For example, Gesler (1993), highlighted therapeutic effects associated with ancient sites of healing, like Epidauros in Greece where, in Classical times, sick

visitors would learn from Apollo's son Asclepius how to heal themselves. Other applications addressed the therapeutic landscapes of thermal springs and spas. For example, Gesler (1998) studied the healing properties of the thermal spring of Roman Bath in Bath in England. Geores (1998) explores how the meaning and symbolism of the metaphor 'Health=Hot Springs' served to commodify Hot Springs, South Dakota, as a therapeutic landscape in the late 18th and early 19th centuries. In addition, research also focuses on the healing properties associated with sites of spiritual or religious pilgrimages, such as Lourdes in France (Gesler 1996) and native American Indian sacred landscapes (Dobbs 1997). Nature represents another important extraordinary landscape, as found in parks and camps. For example, Palka (1999) studied the therapeutic landscapes of Denali National Parks of Alaska. He analyzed the experience of visitors in relation to self-expectation and renewal, arguing that a pristine yet accessible park could help restore, heal and promote wellness. Williams (2007) explores similar ideas in relation to the Swiss Alps and the 'magical' healing properties of high mountains and the alpine world. Research has also addressed the encounters with nature at camps and short-stay locations. For example, Conradsons (2005) studied a respite care center as a therapeutic environment, revealing the impact on enhancing self-confidence for people with physical impairments. Kiernan, Gormley, and MacLachlan (2004) demonstrate the importance of therapeutic recreation camps for reducing self-reported physical symptoms among children with chronic illnesses, supporting their self-esteem.

In contrast to extraordinary therapeutic landscapes, a relatively smaller body of research focuses on the creation of everyday therapeutic landscapes (English et al 2008). However, recent years have seen an increasing interest in healing landscapes of everyday life.

Everyday places are settings and environments where people carry out routine day-to-day activities, such as the home, workplaces, markets and sites of recreation (Chakrabarti 2010). For example, Coyles (2004) demonstrated how the home environment can shape a safe space and a therapeutic landscape for woman diagnosed with environmental illness. English et al (2008) addressed, through in-depth interviews with women surviving from breast cancer, strategies survivors used to heal their minds and bodies at multiple scales of everyday landscapes including body, home, and community (i.e. parks, backyards, gardens). Milligan et at (2004) demonstrated the importance of community gardens for supporting social networks, quality of life and well-being among the elderly population. Other research has considered the gendered and culturally specific dimensions of everyday life spaces. For example, Chakrabart (2010) addressed the links between place and Bengali immigrant women's use of social networks in their efforts to experience a healthy pregnancy.

The third category of healing places is sites of formal health care delivery (ex. hospitals, asylums). English et al (2008) studied cancer support services and sites of alternative healing as therapeutic landscapes for women with breast cancer.

2.6 Therapeutic Landscape as a Framework in Examining Home Modifications:

The home environment is conceptualized in the literature as having 3 primary modes of experience (Lund & Nygard, 2004; Oswald & Wahl, 2005; Sixsmith, 1986; Smith, 1994). These are:

(1) The physical home, consisting of the design, layout and materials in the dwelling. It refers to the space that can be measured and is shaped by function, culture and history (Sixsmith, 1986; Steward, 2000). (2) The social home encompasses relationships with significant others, such as a spouse or family members, who may often inhabit the same physical environment. The social home also includes those who may enter the home on occasion or exert an influence from outside the home, such as relatives, neighbors, friends, and community networks (Dunn, Haney McClain, & Youngstrom, 1998; Rubinstein, 1989; Sixsmith, 1986). (3) The personal home is a place of self-expression, identity, and personal control; and operates as a central reference point in a person's life, encapsulating feelings of familiarity, security, and belonging (Depres, 1991; Dovey, 1985; Sixsmith, 1986).

Given that therapeutic landscape theory encompasses a holistic understanding of place, considering physical, individual, social and cultural factors in the maintenance of health and well-being (Williams, 1999), it presents an idealized framework from which to explore the lived experience and meaning of home by families with children with autism, given physical modifications made to the home environment. Therefore, this research contributes to the scarce research evidence which links home modifications to the well-being of families and their

children with autism. Williams (2002) calls for applying therapeutic landscape theory as a framework for exploring the meaning of home by informal caregivers. She pointed out to the significance of this line of research, which holds also true in case of families caring for children with autism. Williams (2002) argues that such work contributes to the minimally researched area of home as a place of care and of the growing literature on caregivers' continuous struggle in the home environment. Furthering our understanding of the ways that families modify and experience their homes will help both professionals (e.g. architects and occupational therapists), as well as families in the adjustment of the home environment to be therapeutic for all familial members sharing the household with a child with autism. Simultaneously, research results can potentially contribute to the initiation of health care policy through identifying factors influencing family discomfort. In addition, as pointed out by Williams (2002), this line of research will contribute to the continuing development of the concept of therapeutic landscape theory, as well to the ongoing debates in the human and social sciences on the meanings of space and place.

2.7 Chapter Summary

This literature review began with a brief introduction on autism, defining its characteristics and prevalence, as well as introducing the debate on genetic versus environmental causes of the disorder. The literature suggests that the genetic base, together with environmental factors, may explain autism, and that those contextual factors that occur in uteri, during childbirth, or soon thereafter may trigger the susceptible genes. The contextual factors that could influence a child developing autism might be: parental age; low birth rates;

multiple births, or; maternal infections during pregnancy. Contextual variables, including elements of the built environment, also play an important role in trigging autism behaviors, such as aggression, self-injury, property destruction and tantrums. In Addition, people with autism are forced to make an effort to grasp and understand the environment around them because of their difficulty in processing information received through their senses. Many elements in the environment, which other people ignore or block out (such as background noise, flickering light, or a bright color), can be very disturbing to people with autism. Therefore, a built environment designed for non-autistic people exacerbates the daily life challenges of people with autism.

Contemporary architecture has paid attention to the needs of individuals with different degrees of visual, hearing and motor disabilities. However, there is a dearth of research related to architectural design for people with cognitive and sensory impairments, including people with autism. The limited available research has mainly focused on the design of autism-friendly learning environments and new residential environments for adult people with autism. Several design strategies have been suggested in response to cognitive, social, communication, sensory and behavioral autism-related challenges. Despite the fact that most of the identified design strategies can be generalized to other environments, there is an urgent need to specific research on retrofitting existing family homes. Furthermore, research on design interventions in home environments should not only respond to needs of individuals with autism, but also to challenges experienced by their family members.

Physical modifications of the home environment to meet patient's needs have attracted increasing attention due to the recent trend in health care delivery which fosters transferring care from formal spaces, such as hospitals and institutions, toward informal setting, such as homes. A significant amount of literature related to home modifications has been directed to addressing the caregiving of elders and people with physical impairments. Research findings suggest that such environmental interventions have improved their functional performance, lessened their dependency on others, and contributed to the continuation of their daily routine. Fewer research studies have addressed the impact of home modifications on the experienced meaning of home. The findings suggested a positive impact with respect to a sense of comfort, control, identity, and therefore, quality of life for both patients and caregivers. However, there has been little investigation of how home modifications affect the experience and meaning of home in the case of people with mental or developmental disabilities, including those with autism.

Pioneered within the field of health geography, the concept of 'therapeutic landscapes' greatly enhanced the understanding of the place/health relationship by uncovering the way in which the physical and built-environment, social conditions, and human perception interact in creating healing landscapes. A significant amount of early literature is dedicated to analyzing the therapeutic landscapes of places outside the realm of people's day-to-day life, characterized as having an enduring reputation of healing. In contrast, a relatively smaller body of research focuses on the creation of the therapeutic landscape of everyday places where people carry out routine day-to-day activities, such as homes. Given that the therapeutic

landscape concept encompasses such a holistic understanding of place; it presents an ideal framework for exploring the impact of modifying the physical home environment on the lived experience and meaning of home by families with children with autism.

It can be concluded from this chapter that this study contributes to filling research gaps related to autism-friendly home architecture, linking home modifications to the well-being of families and their children with autism, and applying therapeutic landscape theory as a framework for exploring the meaning of home by children with autism and their families.

CHAPTER 3

METHODOLOGY

3.1 Introduction

In this chapter, I will be outlining the methods used when collecting the data used to investigate the following research questions: (1) Using *Therapeutic Landscape theory*, what are the physical, social and psychological challenges that affect the quality of life of autistic children and their families in their home environment?; (2) How can the physical elements of the home environment be designed (or modified) to alleviate these challenges and create an autism-friendly home?

The corresponding study objectives are as follows:

1. To understand the common characteristics of autism that affect the way children with autism interact with their home environment.
2. To explore the common challenges faced by children with autism and their families in their daily life and what features of the home environment are contributing to these challenges.
3. To identify the common home modifications adapted by families to face these challenges.

4. To explore the lived experience of families and their perception of their quality of life before and after adopting home modifications.
5. To establish general guidelines for designing autism-friendly home environments.

3.2 Study Context

The geographical context for this study is Canada and U.S.A, two large countries with a growing number of children diagnosed with autism. Autism is considered the most rapidly advancing childhood disorder. A recent study (Baio et al 2012) indicated that autism now affects 1 in 88 children and 1 in 54 boys in North America.

The research consisted of three phases:

Phase one was aimed at acquiring a general understanding of the challenges facing children with autism, and their families in their home environment. This was achieved through a literature review and via semi-structured interviews with professionals and specifically occupational therapists and architects. This phase required participants who were familiar with the various housing typologies common to North America, specifically Canada and U.S.A. These common housing typologies included: detached houses, townhouses, and apartments.

Phase two was aimed at defining, for each housing typology, the most common challenging physical, social and psychological elements, and the most common modifications adopted to enhance the quality of life of the children with autism and their families. This was

achieved through an online questionnaire that targeted families in the Canadian provinces and nonspecific states across the U.S.A.

Phase three was aimed at exploring the lived experience of families of children with autism and how their quality of life was affected by home modifications. This was achieved through diary interviews with three families, one representing each housing typology. Families living in Mississauga and Oakville (Ontario) with children with autism were chosen as a convenience sample given that the researcher lives in Mississauga.

3.3 Research Design

This study employed a qualitative methods approach, and specifically a case study approach. This form of inquiry was chosen specifically because it focuses on human environments and human experiences within a variety of theoretical frameworks (Hay, 2010). The behavior and experiences of humans may not only be highlighted through their personal attributes, but by their social position 'together with their associated resources, constraints or rules' (Sayer 1992, 93). A case study approach appreciates multiple viewpoints and varied meanings of the experience, which otherwise might be eliminated or ignored. In this study, it's not only important to understand how to best achieve autism-friendly home environments, but to "explore in-depth nuances of the phenomenon and the contextual influences on and explanations of that phenomenon", (Baxter, 2010, p.81; Yin, 2009). This thesis uses Yin's (2009, p.2) definition of a case study, as an "empirical inquiry that investigates a contemporary phenomenon in-depth and within its real life context" (p.18). The phenomenon are the challenges of the home environment where children with autism and their families live, with

those who are directly involved in modifying this environment to be the *unit of analysis.* Given that the *Therapeutic Landscape* theory has been minimally applied to the home environment and never, to my knowledge, applied specifically to children with autism, this study moves toward a 'theory expanding' case study (Baxter, 2010) to further develop the *Therapeutic Landscape* theories while also better understanding the: challenges faced by children with autism and their families; elements that can be best addressed to relax these challenges, and; modifications adopted for a better quality of life for the children and their families.

In the following sections, I will explain in detail the steps taken to collect data in each of the three phases. I will begin by describing the method for participant recruitment and sampling, and then discuss the approach used for data collection and analysis. Since a case study requires multiple sources of information on verification and support (Baxer, 2010; Creswell, 2007), various qualitative methods were used in this study to collect data, including: (1) key informant interviews; (2) a focus group; (3) an online survey, and; (4) face-to-face interviews. The results of each phase informed the following phase.

3.3.1 Phase one: Face-to-face Interviews and Focus Group with Key Informants

The purpose of phase one was to learn from the experiences of professionals who work with individuals with autism. This involved selecting people who could share aspects of their knowledge, ideas and experience that is pertinent to the topic (Minichiello et al.1995, 168). Occupational therapists work directly with children with autism to enhance their interaction with the environment through their daily activities (AOTA fact sheet 2011), while architects

work on shaping functional spaces that meet their daily needs. These key informant interviews aimed to acquire insight regarding the daily challenges in the home environment that affect the quality of life of children with autism and their families, as well as the physical elements that stimulate these challenges. The current trend in autism-focused architecture was explored. In addition to the treatment strategies that is used in occupational therapy.

3.3.1a Method

3.3.1a(i) Architects

The qualitative approach used with architects was the interview method. Interviews are a great method of acquiring information about events, views and experiences, which obviously differ among people of various classes and levels (Hay, 2010). In addition to this, interviews tend to explore complex behaviors and understand incentives (Krueger 1994; Minichiello et al.1995, 70-4; Valentine 1997, 110-12). As Hay (2010) stated, the interviews are intended to fill the "gap of knowledge" that other methods failed to cover completely. This is particularly beneficial in my study due to the limited literature review in this topic as discussed in the previous chapters.

3.3.1a(ii) Occupational Therapists

In addition to using the interview method with the occupational therapists for the same reasons mentioned above, a focus group approach was used via Skype. This method involved a group of people discussing a topic, which is introduced by the researcher. The interaction between participants is the main characteristic of focus groups, providing an opportunity to

hear different opinions and where one comment can provoke a sequence of responses (Hay, 2010). This results in a great deal being derived when compared with other research methods (Berg 1989; Stewart, Shamdasani and Rook 2007).

3.3.1b Participant Recruitment and Sampling

Before recruiting participants, research ethics approval was received from the McMaster University Research Ethics Board (see Appendix A). The components in my ethics application included: a study protocol, recruitment scripts (see Appendices A-1, A-1a, A-1b and A-2), interview schedules (see Appendices A-3, A-4, 1-4a, B-1 and C-2) and letters of information/consents (see Appendices D1,D2a,D2b,D3 and D4).

Prior to starting, all participants were informed of the risks, benefits and rights. A confidentiality statement concerning the protection, privacy and security of research data was read to the participants as well. Although I strongly emphasized that anonymity would be used, and that real names and detailed addresses would not be revealed in the study, all the participants (with no exceptions) had no problem at all with the publication of their names. In fact, I felt that some architects and occupational therapists considered it a kind of advertisement!

Each family in phase three was given $100 cash as a honorarium for their time and their effort in contributing to the study. Participants in each of the three phases were asked to provide contact details if they wished to receive a summary of the study's results. (see Appendix G)

3.3.1b (i) Architects

Criterion sampling, one of the various forms of *purposive sampling* was the strategy adopted for choosing the potential architect participants. Patton (1990) reveals how "information-rich cases" gives the researcher further in-depth knowledge about points of great significance to the study. The criteria for selection included the following: have been involved in designing for people with autism; is a researcher/lecturer in the field of autism, has a personal story with autism, and; has followed-up with their autism-related architecture projects.

Four architects were contacted through a recruitment email (see Appendix A-1). One was from Canada, another from the U.K., and two were from the U.S.A. Although the response I initially received was very encouraging, I consider this phase to be one of the most challenging phases in the study. In addition to the limited number of architects who have been actually involved in designing for people with autism, recruiting them was very challenging because they were constantly occupied and 'on the go'. Most of them had commitments overseas, whether with their projects, lectures or research. This just made me more determined to not lose hope and to keep trying by sending reminder emails. In addition to fulfilling the three criteria above, these architects are considered to be the most reputable in the field of autism-design. Although I initially suggested in my proposal that the targeted number was one to three architects, however the outstanding profiles couldn't be resisted; most of whom are considered 'pioneers' in the field. I was looking to benefit from their experiences, both personally as an architect, and with respect to the study. The following table (Table 3.1) summarizes the unique profile and interview strategy (i.e. Skype, email) for each architect participant.

The architects were asked to sign a consent form (see Appendix D1), then select a date and time at their convenience to conduct a *semi-structured* interview via Skype (chosen to the distance). One of them preferred to send the answers through email. Although an interview schedule was available for use, with questions arranged in a predetermined order (see Appendix A-3), the interview was intended to be semi-structured in order to encourage experts to speak freely about their experiences, as well as to open up new avenues and suggestions to enrich the research. Although there was no restriction to following the interview schedule, there was a constant monitoring of the conversation to ensure that the subject matter of interest was being captured.

Name of Architect	Employer	Country	Experience with Autism	Strategy and Duration	Date
Merilee Meacock	KSS Architects, Architect and Partner	**U.S.A**	Honored architect for contribution in designing Eden Autism Services Center for people with autism ages 3-21	Skype 25min	6-12-13, 3:00 p.m
Cynthia Zahoruk	Principal Architect at Cynthia Zahoruk Architects Inc.	**Canada**	Founding president at Autism Canada Foundation, personal experience with her son, and designer of home to accommodate her son's needs.	Skype 30min	7-12-13, 3:00 p.m
Kimberly Steels	Self employment as a consultant for autism design.	**U.S.A**	University professor in architecture, author of a book on autism residential design and a practioner designer.	Skype 36min	24-1-2014
Simon Humphreys	Simon Humphreys Architect	**U.K**	Worked on multiple special needs and autism projects, lecturer and researcher of papers about autism and architecture published worldwide including Canada, USA and Europe. Personal experience, lived with late brother with autism	Via email	28-1-2014

Table (3.1) Profiles of the architects and their connection to autism

3.3.1b (ii) Occupational Therapists

A total of eleven occupational therapists were involved in this study. As with the architects, c*riterion sampling* was used for recruitment. In addition to their experience related to my research topic, they were also required to fulfill the following criteria: worked with children with autism; worked or were working in the public or private sector in Canada were involved in research about disability, preferably autism, and; provided therapy in either a clinic - based or home- based setting.

I had no problem finding occupational therapists, especially given that their names and contact details were publicly available on the internet. I was able to find two therapists that not only met the previously discussed criteria, but highly exceeded them. Both are members of the College of Occupational Therapists of Ontario with more than thirty years of experience working with children with developmental disabilities, including autism. As previously mentioned, all key informants were comfortable having me use their real names. Sandra Whalen is involved in research with CanChild Center for Childhood Disability, a research and educational centre located at McMaster University in Hamilton, Ontario. The CanChild Center is focused on improving the lives of children and youth with disabilities and their families (CanChild 2014). Both therapists were contacted through a recruitment e-mail (see Appendix A-1), which included information and details related to the research. They were also required to sign a consent form (see Appendix D-2b). With their kind cooperation, a date and time was set for a one-to-one Skype recorded interview. Table 3.2 summarizes the profile of the participants, along with the interview strategy used.

Snowball sampling, which identifies cases of interest suggested by people who know others (Kirby and Hay 1997; Stratford 2008) and *criterion sampling,* previously discussed, are two forms of *purposive sampling* used in recruiting the remaining occupational therapists. I learnt from my supervisor (Dr. Allison Williams) about a group of occupational therapists who meet regularly to discuss various professional issues related to their autism practice. Luckily, a member of this group is the sister of my supervisor (Paula). She is also the host of their meetings which take place at least once a month in her home. I contacted her directly by email (see Appendix A-1-a), asking her if I could implement a focus group as part of one of their

meetings (see Appendix A-1-b). This was also forwarded by Paula to all the focus group members. Although the target was to involve as little as three of the interested members, I was overwhelmed with the higher participation number (n=9). After the group rescheduled the meeting for the second time due to the unpredictable weather conditions this winter, the focus group finally agreed on a mutually agreeable date and time. However, weather conditions at prevented me from attending and i had to join them via Skype. The consents (see Appendix D-2a) which were required to be signed prior to the session were later collected by Paula and sent to me via mail.

For both the one-to-one interviews with the two occupational therapists and the focus group that included the other nine, the *semi-structured* interview was the strategy adopted for the same reason as that of the architects (see Appendices A-3, A-4 and A-4a). Encouraging sequenced but flexible conversation was the key here again (Hay, 2010).

Name	Employer	Country	Experience with Autism	Strategy and Duration	Date
Shirley Sutton	Private OT, College of Occupational Therapists of Ontario, and a member of the Ontario Society of Occupational Therapists.	**Canada**	Over 35 years experience helping children and youth with long and short term developmental disabilities. Services and workshops on a variety of topics related to play, behaviour, gross and fine motor development, and	Skype 45min	9-01-14, 9:00 a.m
Sandra Sahaigian Whalen	Peer assessor with College of Occupational Therapists of Ontario and one of founders of REACH services for OT	**Canada**	Over 30 year experience with children, youth and young adults with disabilities in a wide variety of settings. Also involved in clinical research and resource development with the CanChild Centre for Childhood Disability Research at McMaster	Skype 30 min	14-1-14, 12:37 a.m.
Paula Aquilla & Focus Group	Focus group of 9 occupation therapists working in various places	**Canada**	ranging from 15 to 32 years	Skype 48 min	14-1-14, 05:35 a.m.

Table (3.2) Profiles of the occupational therapists and their experience with childhood disability

3.3.1c Data Analysis: Coding

To analyze the content of the interview data collected, a thematic content analysis of the transcripts was applied. The purpose was data investigation and theory generation (Hay, 2010). Cope (2010) states that coding is a useful method to manage the information in which qualitative data has been gathered. It is how we assess, classify and "make sense" of the data gathered (Cope 2003; Jackson 2001). Appendices (E-1 and E-2) highlight the following steps, which I adapted to develop my tables of themes and subthemes:

1- *Creating a systematic scope for the codes*. Based on the extensive literature review, an interview schedule was developed and major themes were formulated. For the architects, themes included: the current design considerations for people with autism, behaviors addressed in the design procedure; modifications in the homes, and; autism related awareness in architecture. For the occupational therapists, themes included: challenging behaviors during therapy; modifications adapted, and; behaviors that are most responsive to these modifications.

2- *Filtering the content to be analyzed.* I went through the transcripts to search for macro-codes and illustrative quotes that represented the themes to be used later in the research. Insignificant data was ruled out at this stage.

3- *Looking for sub-codes.* Transcripts were read again in a search for sub-codes that were generated from the participant's answers. For example such code that was found related to the various challenges and elements of the home environment.

4- *Creating the initial table of themes and subthemes.* A first outline of the table was written. This included the questions, themes, macro-codes and sub-codes that were previously highlighted. In this stage, codes with relevant meanings were explained. However, other unnecessary codes were removed.

5- *Final table of themes and subthemes is created.* A final review of the codes was conducted to make sure nothing was missed or irrelevant to the objectives of the current phase, the outcome of which was essential to start the next phase of this study, that being the online survey.

3.3.2 Phase two: Online Questionnaire with Families of Children with Autism

The online questionnaire aimed at analyzing the home environment where North American families with children with autism live. This was accomplished through identifying the following : (1-) the most frequent challenging behaviors in the home environment; (2-) the most critical elements of the home environment that contribute to these challenges; (3-) the most common home environment modifications adopted (or recommended) by families to face the challenges and enhance their quality of life; (4-) the ranking of the identified challenging behavior(s), critical home environment element(s), and modification(s) according to their impact on the quality of life in the home environment; (5-) the collection of additional information specific to the housing typology where families live (1- apartment; 2-detached house; 3- town house), and; (6) the cost incurred by families to modify their homes, together with the sources of their funds.

3.3.2a Method

The method used here is the questionnaire survey. This technique is very useful in collecting data about individuals, their behaviors, backgrounds, social relationships, views, and perception of events (McLafferty 2003; Parfitt 2005). It sheds light on trends, views and meanings (Hay, 2010). In addition to minimizing printing and distribution costs (Sue and Ritter 2007), I chose my questionnaire to be online to target a larger population of families in North America.

Before posting the questionnaire online, I made sure that all the questions (see Appendix B-2), were related to my initial research question. Referring to my literature review, together with the results from phase one, I started by writing a list of the concepts that I was seeking to explore in this phase. According to Sarantakos (2005) when describing the process of developing questions for a questionnaire, it's a way of translating research concepts into variables, variables into indicators, and indicators into questions. I also ensured that my intended participants would comprehend them and have the knowledge to answer them through having them edited by my supervisor multiple times. According to Lumsden (2005), the questions should be phrased to suit a reading age of approximately 11 years. In addition to the question content, both closed and open questions were used. Closed questions were usually chosen to capture quantitative data, such as information about participants' profile. These types of questions allow the participants to choose answer options while ranking them to provide a measure of attitudes or opinions (Sarankatos 2005, ch.11). Open questions were used in the survey as well. According to Hay (2010), they are usually better in providing in-depth responses and are usually placed at the end of the survey. By using them, I was able to dig deeper and ask some complex questions to reveal information in a greater depth. For example, 'giving voice' to my participants by using these less structured questions allowed me not only to learn the characteristics of concern in the home environment but, more importantly, to understand the meanings and challenges in the home.

When the questionnaire was ready to be posted online, I had to familiarize myself with one of the commercial survey hosting tools available. I chose *Survey Monkey* as it was a simple tool for beginners. After reviewing a few tutorials on YouTube, and reviewing examples from

fellow graduate students, I was finally ready to start my own survey. After finalizing the content, type, wording sequence, and format of the questions to ensure a successful survey (which is very important when discussing a sensitive topic such as autism), I choose a layout. My aim here was a simple, clear and uncluttered design to ensure readability and to encourage completion. A welcome screen was initiated to introduce the participants to some basic instructions and information, such as: who I am, the purpose of my study and, what to expect in the survey. Risks and benefits to participants were stated, and confidentiality was strongly stressed. This was all followed by a mandatory electronic consent to be signed by the participant prior to the start of the survey (see Appendix D-3). All open and closed questions (see Appendix B-2) were written and numbered. Instructions on how to answer questions were given beside each question. The survey closed with a thank-you and an optional box for participants to share their email or mailing address if they wished to receive a lay report of the study upon completion of the research. The online survey was then ready to be distributed (see link of the survey: https://www.surveymonkey.com/s/6NCJV22).

3.3.2b Participant Recruitment and Sampling

Following ethics approval, as previously discussed in phase one, information about the online survey was sent by email (see Appendix B-1) to well known autism organizations in Canada, such as Autism Ontario, Autism Speaks and Autism Canada. I also sent emails to autism treatment centers and autism support groups across Canada and the U.S.A. However, it was nonspecific to American states. I was targeting all the provinces in Canada. *Criterion sampling* was the strategy for choosing my participants in this stage and the targeted sample was the

families of children with autism with the following inclusion criteria: having at least one child with autism (age 3-16); having at least one sibling, and; lived in the same home for at least one year.

Using snowball sampling, as previously discussed in phase one, I encouraged my participants to tell others whom they know (and fulfill the criteria) to participate in the study. Families started to respond on the 23rd of March 2014; however the uptake of the survey was very slow. I would receive one or two response every other day. This left me really down and frustrated. I had limited time as well. I was also targeting a large number. Usually the secretarial department was the first to receive my email about circulating the survey. I learned later that it needed to be passed through several people before it could be 'approved' for distribution to families. Most of these centers and organizations would send me emails asking for more information. I understood that this process could take months, so I started to use *Facebook* to recruit participants. I began sending messages to non-profit organizations and support groups. I would also send messages to the members of these groups, explaining to them in few sentences about my research, followed by the link to my survey. The messages sent on *Facebook* exceeded 130. The survey ran till the 22nd of May 2014. I was extremely happy to see a surge in the responses reaching 168 families in less than two months. What really surprised me were the emails from families who wished to participate in "this important research", as written by one of the mothers, but couldn't because their children were outside the age limit of the study. Even still, they provided their opinion and views of the topic. The responses received by these families who didn't meet the participant criteria, together with the tremendous

number of participants in a relatively limited time, reflect the fact that families of children with autism appear to 'trust' research. Most truly believe that it is a promising way forward.

3.3.2c Data analysis: Coding and Descriptive Statistics

Upon completion of the two-month data collection period, the data were summarized using thematic content analysis, as previously discussed in phase one (see Appendix E-3). Descriptive statistics were also created for the entire sample to describe the participants and results. This included analyzing the data viewed as most significant. The results were used to inform phase three.

3.3.3 Phase Three: Narrative Diary Interview and Field Observation with Selected Cases

This phase aimed at exploring the in-depth lived experience of families with children with autism in their home environment, while better understanding their daily challenges in their home environment. Further, this phase explores any modification made to home environment, as well as how such modifications contribute to improving quality of life. The results from phase two informed this phase by suggesting popular modifications and asking the family's perspective on the likely result specific to their improved quality of life.

3.3.3a Method

Three selected case studies of families of children with autism living in Mississauga and Oakville (Ontario) were chosen for a narrative diary- interview and observation. Diary-interviews encourage participants to take photos and personalized journals of their daily

routine experiences, thoughts and feeling and record them in a written form where these texts are considered the basis for one or more in-depth interviews (Hay 2010). This technique is most informative when seeking a deeper insight into the lived reality of a specific setting. The interview questions were addressed about their quality of life before and after modifications were made in the home (n=2 interviews). The interviews were conducted in the homes of these families. As in previous phases, a letter of information about the study was given to each family with risks and, benefits and rights read to or by the participant to ensure clarity and to answer any questions. It was also noted that the participants would receive $100 cash, $50 after each of the two interviews. Participants were asked to sign a consent form (see Appendix D-4). Face-to- face diary- interviews, which were all audio- recorded, included open and closed questions (see Appendix C-2). Each of the two interviews was one week apart for each of the three cases.

The first interview (averaged 40 mins.) looked at the child, family and the house profiles including the challenges experienced in the home environment. Then a small diary booklet was handed to the family to record the daily-if any- physical, psychological or social challenges experienced by the family members as a result of the child's behavior or an inadequate home environment. After one week, a second face to face interview took place with each family (averaged 20 mins) to discuss the data collected specifically the modifications adopted or wished to implement but couldn't to face these challenges. Field observations and hand-written notes were also taken periodically by me (the researcher) throughout the two interviews. Although it was an *uncontrolled observation*, I was very conscious of what, how and when to observe since the setting of the home is of a very private nature. With the consent of the families, photos of the physical home environment were also taken, which included some of

the challenges and the modifications adopted. The watching, listening and 'being a part of the experience' myself helped me to deeply understand the context of the place and to collect additional descriptive data.

3.3.3b Participant recruitment and Sampling

The three cases were selected using purposive snowball and convenience sampling with the following inclusion criteria: participant families represent one of the specified housing typologies (1- apartment; 2-detached home; 3-town house); families live in the GTA; families have been living in the house for at least one year, and; families include a child diagnosed with autism for at least one year.

I recruited the case studies for this phase with the assistance of a very friendly occupational therapist, which I've known via one of the autism centers in Mississauga. I emailed her seeking her support in finding families who live nearby and are interested in participating. She responded immediately suggesting a few families. I then forwarded a recruitment email (see Appendix C-1), where families could read all research – related information. Within couple of days, I was in email contact with three families of children with autism living in Mississauga and Oakville. The surprise was that each family represented one of the three housing typologies previously stated.

After setting the date and time by the first interview, I met the mothers. The first family lived in a townhouse and had a son with severe autism. The second had a son with non-specific Pervasive Developmental Disorder (PDD-NOS), a mild form of autism. They lived in a nice

spacious detached house. The third, which lives in an apartment, has a son with mild to moderate autism. After conducting my interviews and observations, I couldn't help but think of the common characteristics these mothers shared beyond the criteria mentioned above; they were incredibly friendly and welcoming, they allowed me to take many photos of their 'private' homes, they had no problem publishing their names or their son's names, and they all refused to take the $100 honorarium. I had to insist that they take of as an appreciation for their time. They were continuously saying that they are not doing this because of the money. Again, this also confirms the strong belief in academic research among this population. I believe that these mothers are seeking all kinds of support. This was evident to me from the conversations they were initiating before and after recording the interview. One would talk to me about her struggle with her child's school; another would tell me about her challenging life after her husband's death. These and other topics unrelated to my research were discussed. I was glad to get involved in the lives of these families. These mothers just wanted to be 'heard'. This not only helped me in knowing more about their backgrounds, social location and perceptions but also established a friendly informal relationship, usually not present between the interviewer and the interviewee. This helped them to talk freely and sometimes 'cry' without the fear of being 'judged'.

3.3.3c Data Analysis: Coding

As applied in the previous two phases, thematic coding was used to analyze the content of the data collected; a thematic content analysis of the transcripts from the interviews within the case studies was applied (see Appendix E-4).

3.4 Establishing Rigour in Qualitative Research:

Establishing rigour is essential to ensure reliability and validity in qualitative research. According to Baxter and Eyles (1997), there are relatively few standardized procedures for evaluating this; there is a critical need for establishing criteria in evaluating qualitative research. The main principles used to guide assessment and integrity must therefore ensure credibility, transferability, dependability, and confirmability. Subsequently, several criteria were used in this study in order to evaluate trustworthiness, including those suggested by Baxter and Eyles (1997) for evaluating qualitative research (see Appendix F).

To ensure validity of the study, purposeful sampling and referential adequacy was emphasized which also enhanced the credibility of the study. For example, the semi-structured interviews with the limited number of architects who have experience with autism-related design, were accompanied by an extensive literature review in an effort to come up with the most influential architectural elements affecting the behavior of the child with autism in his/her home environment. In addition, for all interviews the use of clarifying questions, taping and transcribing, and returning them to the participants to amend if requested, was applied.

Credibility was also addressed by asking participants to use diaries in phase three; this allowed information to be captured from the perspective of the mothers, in their own manner of communication, and in the context of the real world. The information was conducted over a longer period of time, allowing for a wider and more irregular set of data to be collected. It also enabled me, as a researcher, to gather data at time intervals that are potentially difficult to

capture using other methods, while being less intrusive given the private nature of the home environment.

In an effort to enhance the transferability of the results within contexts outside the study situation, the methods and their effectiveness were reported in detail to develop a thorough understanding, thereby enabling a future researcher to repeat the work.

Dependability was stressed by using overlapping methods, such as the focus group and individual interviews. All interviews were also recorded comprehensibly using audiotapes. Further, a detailed transcription of each interview was provided, strengthening the reliability of the research study.

Dependability was also enhanced through the probing of themes derived from participants' earlier responses. For example, two interviews were implemented with each family to determine their opinions about the challenges they face raising a child with autism at home. In this way, I was able to 'test' if all the participants had the same views about my themes. Building trust also assisted in producing trustworthy results.

Data triangulation included various sources, such as: interviews, structured survey questionnaires, and; observations to ensure rigour in data analysis and reduce the influence of researcher bias. According to Baxter and Eyles (1997), triangulation is one of the most powerful techniques for reinforcing credibility. It is based on the concept of 'convergence' where similar findings, provided by various sources, strongly support the credibility of the research. The use of quotations from several different participants to confirm reoccurring themes also provided multiple source triangulation (Baxter & Eyles, *1997).*Achieving investigator triangulation was achieved through discussions on method, findings and interpretation with my supervisor.

Confirmability was achieved through: triangulation of data; the use of diagrams as an audit trail, and; acknowledgment of the researcher's beliefs and assumptions.

Measures for credibility, transferability, dependability, and confirmability can also be strengthened by thick description. Baxter and Eyles (1997) stated that detailed thick descriptions are methodological strategies that explain how constructs and hypotheses are developed and how meanings are derived. The use of thick description provided the credibility for the study and the researcher's strategy for trustworthiness in concept-to-data matching. In addition, the use of thick description was also important for transferability. Although this research is restricted to a particular context, the transferability of this study may still be possible as a result of thick description (Baxter & Eyles, *1997).*

3.5 Chapter Summary

In this chapter, I have outlined the data collection methods used in the three phases of my research. Purposive sampling of key informants was used to conduct semi-structured interviews in phase one. The same sampling method was used to accomplish the online questionnaire for families of children with autism across Canada and U.S.A in phase two. Finally, purposive convenience and snowball sampling was used to conduct the narrative diary-interview for phase three. Thematic content analysis of verbatim transcripts and the establishment of themes and subthemes were applied for each of the three phases.

CHAPTER 4

FINDINGS

This chapter describes the findings of the three research phases: face-to-face interviews with architects and occupational therapists, the online questionnaire survey with families, and the diary-narrative interviews and field observation with selected cases.

4.1 Findings of Phase One

As described in the previous chapter, the purpose of phase one was to learn from professionals who are experienced in building or modifying the home environment to make it autism friendly.

4.1.1 Interviews with Architects

The architecture literature reviewed in Chapter 2 indicated considerable academic interest in educational and learning environments. Architects have proposed various design strategies in response to autism-related challenges identified in such environments. It has been argued that these strategies can be extrapolated to the home environment. The purpose of the interviews is to verify this claim by exploring the most common challenges and design strategies that architects consider while designing homes for families with autism. In addition, the appropriateness of the two main housing typologies (houses and apartments) for creating autism-friendly environments is also discussed. Further, architects were encouraged to

evaluate the degree to which the current trends of architectural practice and education consider the needs of people with autism. A complete list of identified themes, subthemes, and codes is presented in Table 4.1 and will be discussed in the section that follows:

Challenges and home design strategies		
Sub-themes	Coding	
	Challenges	Design strategies
1. Social & communication	Limited or lack of sociability Easy distraction Preoccupation with details	Organize space into zones with different gradations. Provide generous spaces to allow for larger personal zones
2. Sensory	Noise & visual dysfunction (hypo & hyper) Sensitivity to heat	Provide quality acoustics to control noise Maximize natural lighting Avoid traditional florescent lighting Have a sensory-free room in the house
3. Imagination & perception	Difficulty to generalize	Space simplicity and sense of order
4. Safety	Elopement Lacking a sense of danger	Provide locks for windows and external doors Restrict access to kitchens, bathrooms, and laundry
5. Behavior	Aggressiveness and destructiveness Obsessive behavior (e.g., fascination with water play) Toileting behavior Vocal stereotyping Gross-motor behaviors (e.g., jumping, bouncing, climbing)	Utilize clean and durable materials Using sensors to control water usage Remove climbable objects Ensure appropriate wall fixing of elements Provide wider spaces and higher ceiling Avoid any product with toxic chemicals
Houses vs. Apartments		
	Outdoor space Flexibility Quality of construction material	
Professional and academic interests		
	Negligent current housing design trend Lack of interest among practitioners Lack of disability education Personal stories as main motivators	

Table (4.1) Themes and codes identified from face-to-face interviews with architects

4.1.1.1 Common Autism-related Challenges and Home Design Strategies

The most commonly cited challenges and related design strategies have been identified and organized into five categories (subthemes): social and communication, sensory, imagination and perception, safety, and behavior (presented in Table 4-1). Each of these will be further explained below:

1. ***Social and Communication Challenges***

Lack of sociability and the tendency to be alone were two common autism-related challenges mentioned by architects. Kimberly Steels, one of the interviewed architects, states the following:

> *You need to figure out how to design to allow people to be in a place with other people but not in the midst of it. Ah, so what I'm finding with my daughter and her autistic peers, as well as with adults with autism that I have worked with, is that they don't necessarily want to be alone, they kinda want to be in it but don't want to be the focus. Want to be part of the group but not to be in the group doing what the group in doing. So, it is important to design a space that has different gradations.*

This challenge is addressed in design by organizing the home spaces or furniture into zones of different sizes, where the child with autism can engage in family activities without being the focus. Spaces should also be generously sized to allow for a larger personal zone for the child and to provide opportunities for interaction with peers and therapists.

2. Sensory Challenges

Sensitivity to noise, either hypo (i.e., a lack of sensitivity) or hyper (i.e., being overly sensitive), is a major challenge according to the interviewees. Most children with autism are annoyed by noise (hypersensitivity). On the contrary, children with vocal stereotyping behavior (e.g., continuous singing) or hyposensitivity (demanding continuous noise) are disturbing to other family members. In both cases, acoustic insulation and soundproofing should be considered, as suggested by Kimberly:

> *If you are doing a ground up construction, you wanna put that in the beginning because then it accommodates anybody, any kind of possibility.*

Visual sensory dysfunction is another common impairment among children with autism. Merilee pointed out that design strategies to address this challenge include:

> *Providing access to natural daylight, and soft colors and finishes* and avoiding *florescent light*.

Some children with autism are less sensitive to heat which may put them in risk as pointed out by Kimberly:

> *She's one of the ah folks who doesn't have a lot of sensitivity to heat. So it wouldn't be beyond her to touch a hot burner.*

The overwhelming sensory input may trigger negative autism-related behaviors such as aggression and repetitive movements. It is therefore important to have a `sensory-free room` or `sensory space` in the house where the child can retreat to reduce sensory input and relax.

This space can also include other tools to reduce anxiety associated with sensory input as suggested by Kimberly:

> *I think with-a lot of times those behaviors can be ameliorated if there's an opportunity for people to go into a space that can get some of that out. Right, so sensory rooms' or 'sensory spaces' are very important where you can bounce on a ball, where you can jump, you can swing, a lot of times this kinda of help reduce some of those anxieties ... about the space and what's happening in that space*

3. Imagination and Cognitive Challenges

The difficulty in generalizing is an important autism-related cognitive challenge mentioned by the interviewees. The child with autism may not be able to generalize what he learns in school or the clinic to another place because the environments are different. Therefore, it is important to design the home environment such that it accommodates different therapies and learning activities. Kimberly expressed her experience as an architect and a mother of a girl with autism:

> *I prefer to have therapy in the home because then my daughter is learning things within her environment. One of the issues with kids with autism is the ability to generalize. So, what you learn in the clinic might not connect—it is the same thing I did there, no I am going to do at home.*

Difficulty in anticipating what is behind doors is a common imagination challenge for people with autism. The architects stressed the importance of providing the ability to help the children anticipate:

> *...preview a space … to be able to see what's happening in the space before all of the sudden standing in the middle of the space … or to have multiple entrances and exits to a space like a kitchen or a living room so you are not just standing in the middle of them.*

4. *Safety Challenges*

Elopement, that is, the tendency to escape from home, is one of the top autism-related challenges noted by architects. Design strategies to address this challenge range from using low-tech locks or deadbolts to sophisticated security systems. Kimberly explained:

> *Elopement is a big one. You know a lot of kids with autism elope. So how you construct the house in a way that it is not institutional but you are aware when someone is trying to open a window or trying to get out of the front door or any of those kinds of things.*

The lack of a sense of danger among those with autism is another concern for architects. Merilee pointed out design strategies frequently requested by families:

> *We also hear frequent requests for safe and controlled access to kitchens—as there are great vocational opportunities in a kitchen; however, potential dangers related to utensils or equipment use ... within all spaces, to aid in observation and safety.*

Children with autism, especially those with hyposensitivity, may seek stimulation by chewing dangerous materials. "... *she chews on her bed frame, so you want products that don't have toxic chemicals. That's really important*."

5. Behavioral Challenges

In designing an autism-friendly home, the architect should consider many challenging behaviors commonly found among children with autism. Aggressive and destructive behaviors necessitate the use of durable materials. Kimberly explains:

> *So, I think that's where a lot of those aggressive behaviors or negative behaviors come out because there's anxiety about the space and what's happening in that space.... Durable materials would be required to accommodate autistic occupants.*

Jumping, bouncing, and other gross motor behaviors should also be considered when designing autism-friendly homes. Kimberly suggested that wider spaces, higher ceilings, and larger areas are required to accommodate these behaviors:

> *I think one of the biggest ones that I have noticed when I have toured a number of homes and places, when I have tried to design for this population, is trying to make the space look "homey" but accommodating for big gross motor behavior. You know jumping, bouncing, that is something that affects a large percentage, because many people with autism, and kids especially, they haven't really learned how to manage those things at all.*

Climbing up bookshelves and similar structures is "*a major issue for a lot of parents. Removing climbable objects and having well-fixed elements is necessary*."

Obsessive behaviors, such as "*fascination with water play,*" are common among children with autism. Architects apply several design strategies to avoid associated chaos, as described by Kimberly:

> *She plays in the water, wants to play in the toilet, wants to play in the shower. Anything with water, and in fact, she's flooded the bathroom and the hallways several times because there's a real kind of fascination with how it works. So how do you modify the bathroom and the kitchen in order for that to be toned down or so it can't happen? University of Washington researchers are working on developing sensors in the sinks and the showers, so that it will tell you how much water is being used and also shuts off after a certain time, which is very important.*

Obsession with food is another problematic behavior to be considered in design. Merilee pointed out, *"... Also isolated pantry or refrigerator areas address residents who obsess over, or steal food*."

Having a sensory-free room or "quiet space" at home is important for reducing negative behaviors as mentioned earlier. Cynthina, an interviewee, pointed out to the importance of having this quiet space in public buildings to create autism-friendly community:

> *Very limited places they can go out to without feeling embarrassed or "disturbing others". Request for the extra space in the back of the church to be specified for cases like hers who need" quiet space."*

4.1.1.2 House vs. Apartment

Among the two main housing typologies, house and apartment, the interviewees suggested that the former often better accommodates the needs of individuals with autism and their families. Having a secured outdoor space or a backyard is an advantage for children with autism, as it "... *gives a lot of opportunities there*." The house also provides flexibility for changes and modifications especially that apartments are often rentals, as suggested by Kimberly, *"... your 4 walls are your 4 walls, not somebody else's*." Finally, the construction of low-cost apartment complexes may lack quality soundproofing. This can be very uncomfortable for the neighbors. As pointed out by Kimberly, "... *things can get really loud when a kid with autism is living with you.*"

4.1.1.3 Professional and Academic Interests

The interviewees evaluated the extent to which the current housing design trend considers the needs of people with autism as "very poor to nonexistent." This can also be generalized to other places in the community. As Cynthia suggests, there are "v*ery limited places they can go out to without feeling embarrassed or disturbing others…There is a need for more accommodation in public spaces for people with autism*." The lack of interest and

knowledge among professional architects regarding design for disability in general, and for autism in particular, is noted by all the interviewees. Design for disability and autism is also absent from architectural academic curriculums. Kimberly states, "*... absent from design education because it is not an interest. It is not an interest across the board for all architects or landscape architects*."

It is interesting to note that three out of the four interviewed architects have developed an interest in design for autism because they were motivated by personal experience. Each of them has either a child or a sibling diagnosed with autism.

4.1.2 Interviews with Occupational Therapists (OTs)

Occupational therapists work directly with children with autism to enhance their interaction with the environment. They also provide advice to families regarding necessary home modification for successful therapy and quality of life. The interviews with OTs aim to explore: (1) their perspective on the optimal environment for home therapy; (2) the most common autism-related behaviors caused by an inadequate environment; (3) the most common home modifications adopted by families, and; (4) the autism-related behaviors that are best addressed by these modifications. Further, OTs were asked their understanding of which housing typology (house or apartment) would provide a better opportunity for therapy. The main themes and codes are presented in Table (4.2).

Main themes	Codes
1- Optimal environment for home therapy	Clinic vs. home therapy Considerations of selected therapy space
2- Common autism behaviors associated with inadequate environment	Distractibility Restlessness Repetitive behavior Elopement Clumsiness Self-injury Aggressiveness Obsessive behavior Avoidance
3- Common home environment modifications	Modifications related to mobility Safety-related modifications Quiet space Space organization and cluttering Sensory-related modifications
4- Behaviors addressed by modifications	Engagement and focusing Repetitive behaviors Anxiety
5- House vs. apartment	Available area Availability of outdoor space Neighbors Flexibility of change

Table (4.2) Themes and codes identified from interviews with OTs

4.1.2.1 Optimal Environment for Home Therapy

OTs provide several types of therapy, including: perceptual motor therapy, daily living training, social interaction training, and auditory processing therapy.

Clinic vs. Home Therapy

The majority of services provided by the interviewees are conducted in the child's home environment. However, depending on where they work, some OTs provide only clinical therapy. The work of OTs is very client centered; therefore, working in the "*natural setting at home*", where the client lives, is essential for providing personalized service. OTs will be able to suggest

skill-enhancement strategies that can be implemented by the families within the available resources at home. As pointed out by Sandra, an interviewee with 35 years of experience:

> *We find working in the client's home ... we are better able to target our strategies to the challenges they are having at home that are important for the family.... And, help the families learn strategies they can implement in their home environment ... from our experience and philosophy, gains or changes that are made in the clinic don't generalize to the home setting.... Because of the difficulties kids with autism have generalizing.*

While providing services in the client's home, an OT also has a better opportunity to suggest necessary modifications to the home environment. Sandra pointed out:

> *We can see the environment at home, if we need to add visuals or things. We're doing it, we can take pictures of the things at home, we can do it right in that environment ... those of course, are easier to identify and implement when you are in that environment.*

However, to achieve better results, this step should only come after assessing the child's needs and impairments.

Ideal space for Therapy at Home Environment

Choosing the ideal place at home to conduct their service is a challenging task for OTs, as it varies with the particular challenges and sensory sensitivities that the child has. OTs spend time "... *trying to figure out what kind of an environment that particular child responds well to*" and which environment will distract him/her. For example, if he/she is sensitive to noise, a quieter place should be sought. As pointed out by Sandra:

> *I would want to do a sensory profile to understand what their sensory processing patterns are.… My ideal treatment space in home is one where I can match the characteristics of it to that child's sensory processing pattern*."

However, the interviewees described some general characteristics of preferable therapy space. These included: a large area to accommodate the required gross motor equipment and furniture (e.g., trampoline and therapy table); lack of clutter to avoid distraction, and; availability of daylight. However, the interviewees highlighted the importance of doing therapy in different places in the house, as most children with autism lack the ability to generalize. Nadia, a member of the focus group, suggested: "… *it's really important to move around the house. It also gives you a better picture of the child's ability to tolerate different spaces."*

4.1.2.2 Common Autism Behaviors Associated with an Inadequate Home Environment

The interviewees identified and ranked a list of behaviors that can be attributed to an inadequate environment at home. Distractibility topped the list. Depending on the type of sensory sensitivity exhibited by the child, environmental factors such as noise, bright light, cluttering, room temperature, or smell can be the cause of distraction. Restlessness, or the inability to sit and focus, is the second most common environmental-related behavior identified by the interviewees. Many environmental factors can contribute to this behavior include, for example, "*… noise, or bad seating* area, *or lack of personal space*." Perseverative (or repetitive) behavior, such as repetitive language or movements, is the third commonly cited behavior. A child with autism may exhibit such behaviors if he finds "… *something that is highly motivating for him, like letters and numbers on the wall or a picture of animals, if he likes animals."* Other identified behaviors triggered by sensory input include elopement, clumsiness, self-injury, aggression, obsessive behavior, and avoidance.

4.1.2.3 Common Home Modifications Suggested by OTs

To cope with these challenging behaviors, OTs usually advise families to introduce certain modifications in their home environment. The interviewees were encouraged to share the most common modification strategies they recommended. Modifications related to mobility were most frequently recommended by the interviewees. Sandra explained:

> *The kids are really sensory seeking, so they need to be constantly on move, crashing into things, rolling, very physical ... a child like that needs that space, probably needs safe equipment that they can use to get the sensations they're seeking.*

In such cases, it is necessary to maximize the space available, which could be a challenge, especially for families living in small apartments. Removing or adjusting furniture is a common strategy. A lot of families, said Paula, a member of the focus group, "*take out their dining room table and put a play structure and a trampoline and somewhere to climb ... so the child has a lot of movement."* Other families with large houses dedicate specific places, probably in the basement, as pointed out by Sandra: "... they made almost like a mini clinic ... they have all sorts of equipment and activities."

Safety-related modifications are also very common. OTs usually "… *work with families to walk through the house and look at the potentials for safety issues."* Safety strategies may include: using locks on doors and windows and keeping them out of the reach of the child; fixing gates on the stairs, and; using alarms on the doors. Safety strategies for the bathrooms and kitchens include: treatment for the floors to avoid slippage—especially in the case of children who have epilepsy with autism;—keeping the fridge locked, and; keeping the stove and microwave unplugged when not in use. For children who tend to elope from the house, a GPS tracking system is recommended. In the case of self-abusive or aggressive children, it is

necessary to minimize the objects in their environment and furniture with sharp edges. Paula, a member of the focus group, said: "*... the only thing in his bedroom could be a mattress and a television, but the television was behind Plexiglas, and the parents could only access*."

Providing a "*quiet space*," where children can escape from overwhelming sensory input or uncomfortable social situations, is a good strategy for families to adopt. This space should be different from the therapy space. Nadia, a member of the focus group, described this space as "*… a defined small space in the home that their child might enjoy as quiet, calming, relaxing kind of space*." Families use different design solutions, depending on the size of their unit, to create such quiet spaces as pointed out by Sandra:

> *A lot of families have taken out closets for storage and created quiet space for their children. They put pillows in there and put some Christmas lights, so it's just some white, soft light and maybe some fabric or curtain for them to go through*.

Space organization and decluttering-related modifications are important to avoid distraction and improve some skills. Heather, a member of the focus group, discussed a piece of advice given by a speech pathologist: toys should be organized and put out of the reach of children. This will induce them to request for their toys and improve their speech skills.

Sensory-related modifications are also needed in the home environment, especially sound proofing. Using soft colors and light is also helpful as some children with autism struggle with the transition to sleep time. It is important to avoid flickering lights or low quality lighting that emits a sound.

4.1.2.4 Behaviors Addressed by Modifications

The interviewees were unanimous in listing the positive outcomes of home modifications in alleviating challenging behaviors and also in improving engagement in various therapy activities. Shirley suggested that it is easier to *"… get them engaged if you can get them away from distractions or the noise."* The level of improvement, however, tends to vary from case to case. Repetitive behaviors, for example, usually reduced on creating a quiet space for the child to relax from sensory stimulation. However, a successful home modification plan should seek to balance the tailored environment to suit the child's needs and the real world. Paula, a member of the focus group, explained this important concept:

> *It is important for the environment to be tailored to the child … create a space that is relaxing for them … but also help them to be able to manage a little bit of what's there in the real world.… Not so different than life outside that they can't move out their front door.*

4.1.2.5 Houses vs. Apartments

In comparing the two main housing typologies, house and apartment, most interviewees found that a house provides more space to accommodate structures for gross motor activities (e.g., large tube swirly slides), which are difficult to install in an apartment. A quality outdoor *"… incorporated with natural materials … not just a concrete playground"* can be very positive for children with both hyper and hypo sensitivity, as pointed out by Sandra:

> *Many kids with autism have sensory seeking behaviors and that outdoor space allows for movement, smell, different noise, different touch sensations, that you can't necessarily get inside. On the other hand, for children with very sensory sensitivity that might be overwhelming for them, but they still need to learn how to cope with it, so that they're not housebound and they can manage going out.*

Apartments may impose other limitations on the work of OTs given their proximity to other neighbors, as pointed out by Paula, a member of the focus group:

> *When you're working in an apartment, you have to be so conscious of the other neighbors because already the family is generally not on very good terms with the neighbors because of the child's vocalization or thumps or whatever*.

The first phase of this research, as described above, provided responses to the research questions from the perspectives of the professionals (architects, OTs) who are evolved in creating autism-friendly built environment. The most common challenges and related modifications in home environment were identified. The information gathered in the first phase was pivotal in preparing the online questionnaire for phase 2 which will be described in the next section.

4.2 Findings of Phase Two

This phase attempts to respond to the research questions from the perspective of families living with children with autism. The findings presented in this section are based on the responses to an online questionnaire targeted at families having children with autism and living in Canada and the USA. Families were asked to share: (1) their demographic characteristics; (2) their housing profile; (3) the prevalence of autism-related sensory sensitivities; (4) the autism-related challenging behaviors displayed by their children in the home environment, and; (5) the (a) psychological, (b)social, and (c) physical challenges faced by them as a result of having a child with autism at home. Families were also asked about (6) the physical modifications they had introduced in the home environment to alleviate these challenges and improve their

quality of life, as well as the extent to which they were satisfied with the result. It should be noted that the aim was not to achieve a statistically significant result but rather to gain insight into the experiences of the targeted families. Descriptive statistics as well as the main themes derived from qualitative analysis of the responses to open-ended questions are presented.

4.2.1 Geographic, Demographic and Diagnosis Profiles

Of the 168 survey respondents, the majority (72%, n = 121) lived in Canada, of which 60% (n= 73) were from Ontario [population of 12 million].

The majority (50%, n = 84) of the surveyed families had a household size of four people, including the child (or children) on the autism spectrum. The mean age of the child on the spectrum was 8.3 (ranged = 3 to 16), and 7% of the families (n = 11) had more than one child on the autism spectrum. The majority (48.3%, n = 81) of the children on the spectrum were diagnosed with autism, and the diagnosis for the rest were distributed among Asperger's disorder, high functioning autism, and pervasive development disorder (PDD). The severity in almost half of the cases (n = 81) was moderate, while 30% (n = 50) was mild (Figure 4.1).

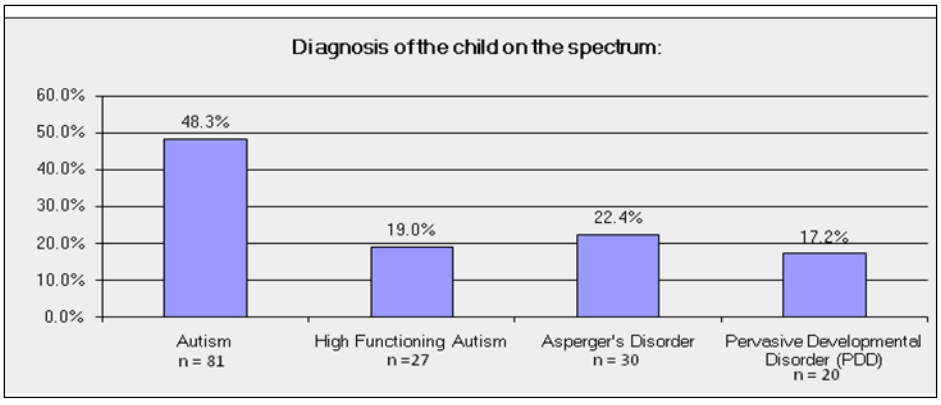


Figure (4.1) Diagnosis of children on the Autism spectrum

4.2.2 Housing Profile

The majority (70.2%, n = 117) of the surveyed families lived in detached houses, with 20.6% (n = 33) living in attached (townhouses), and the rest (n = 18) living in apartments. Almost half of the housing units (n = 82) were medium sized (4 to 6 rooms) and 45% (n = 76) were larger units with over 7 rooms. The majority of the families (58%, n = 97) had been living in the same house for more than 4 years.

Most of the families (84%, n = 141) had managed to ensure a separate room for their children on the spectrum. However, only 58% (n = 10) of the families living in apartments could do so.

4.2.3 Therapy Space

The majority (72%, n = 120) of the children on the spectrum received home therapy. The child's bedroom or a room dedicated to therapy was used for home therapy activities only in 18% (n = 30) of the cases; 36% (n = 60) of the surveyed families used their living rooms as therapy space, and the rest used different rooms in the house for therapy, including the kitchen, bathroom, basement, and dining room, *"... depending on where skill needs to be learned,"* as reported by a respondent (Figure 4.2) i.e. toileting in bathroom an eating in dining room.

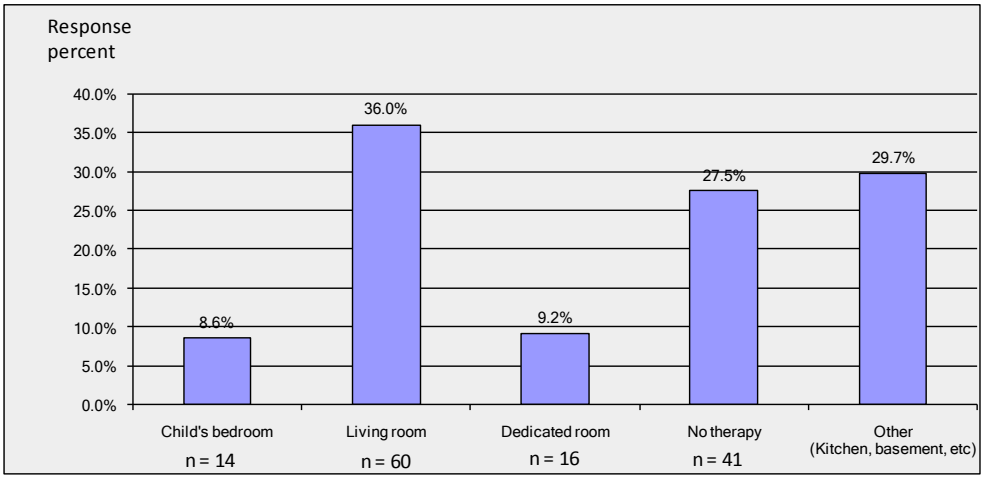


Figure 4.2 Therapy locations.

4.2.4 The Prevalence of Autism-related Sensory Sensitivities

Noise: The majority (87%, n = 146) of the respondents reported that their children were sensitive to noise. With regard to noise sources, 73% (n = 122) of the children on the spectrum were disturbed by external noise, especially traffic and rain, and about 80% of the children (n = 134) were disturbed by noise generated from within the house. Other family members (e.g. siblings) were identified as the most common (35%, n = 35) source of internal noise, followed by noise from household appliances (e.g., vacuum machine). Figure 4.3 presents a list of noise sources and the sensitivity levels, as reported by the respondents.

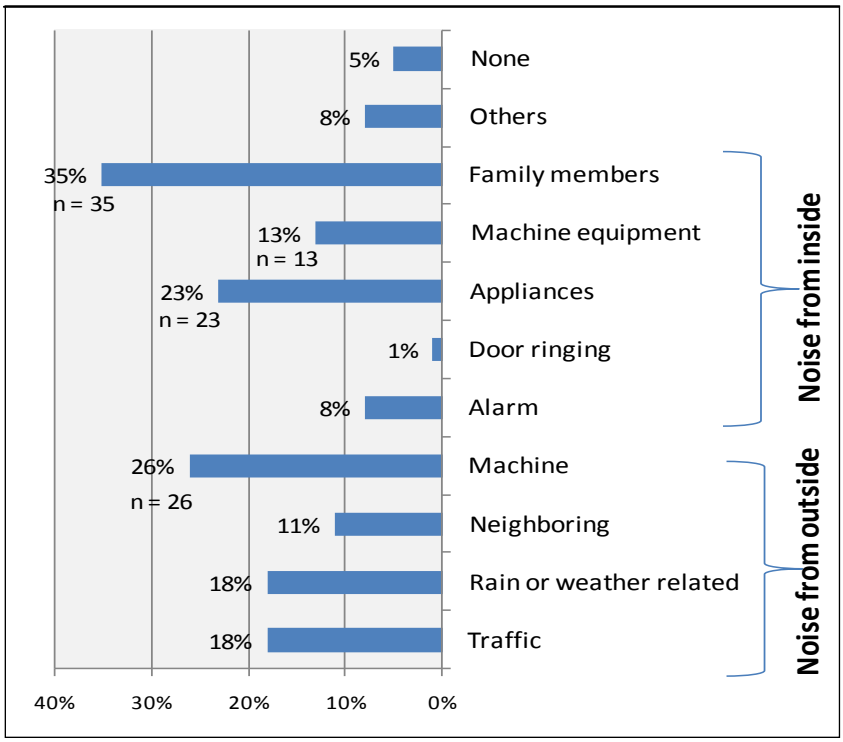


Figure 4.3 Noise sensitivity and sources

Visual sensitivity: Disturbance by visual stimuli at home was the second most commonly reported problem (67%). Disturbance by indoor sights was reported by 27% of the respondents (Figure 4.4). For example, a respondent commented that her child could not handle *"... seeing food left out or uncleaned surface."* Another respondent reported that *"mirrors and reflective surfaces"* disturbed her child on the spectrum. Disturbance on seeing clutter was reported by 26% of the respondents. One commented that "*He cannot handle the house to be the least bit dirty or messy."* Disturbance caused by outdoor scenes or activities such as "*... wind, falling leaves, snow, rain"* was reported by 19% of the respondents.

Light sensitivity: Sensitivity to light was the third most commonly reported (66%) sensitivity by the respondents (Figure 4.5). Sunlight was the greatest source of disturbance (32%, n = 32) followed by flickering light (26%, n = 26).

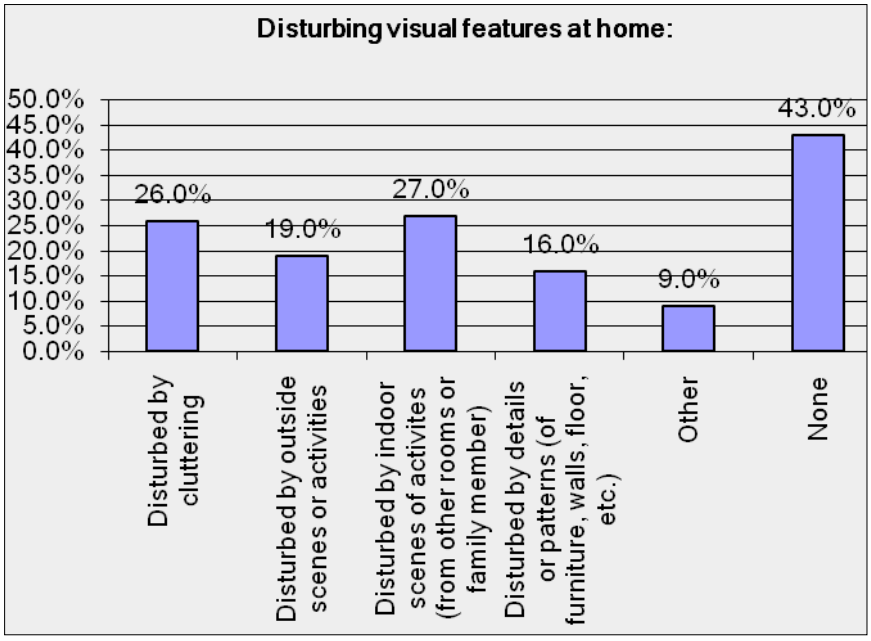


Figure 4.4 Sources of visual sensitivity

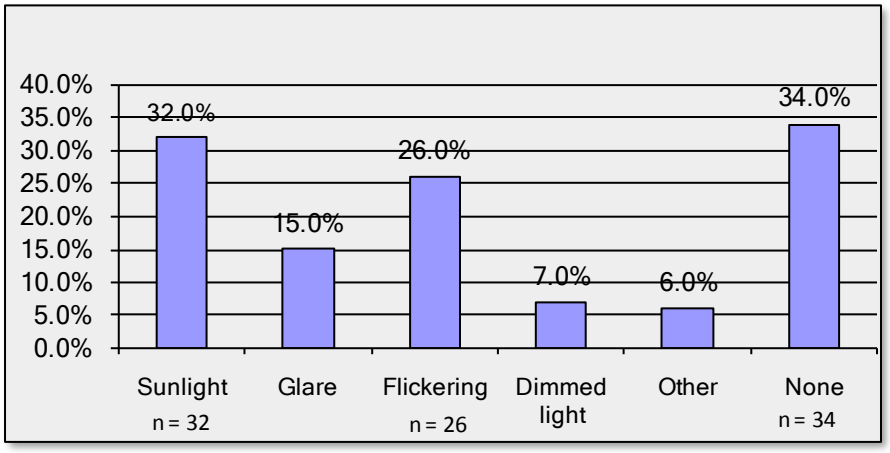


Figure 4.5 Sources of light sensitivity

Temperature: Sensitivity to heat and cold were reported by 54% of the respondents. The majority (35%) of the children on spectrum were sensitive to heat.

Smell: Sensitivity to smell was less common with only 50% (n = 50) of the respondents citing it as a problem (Figure 4.6). Almost one third of the respondents (36%m n = 36) reported sensitivity to indoor odor, while 30% reported disturbance caused by outdoor smells.

Colors: Surprisingly only 20% (n = 20) of the respondents said their children were sensitive to specific colors (Figure 4.7).

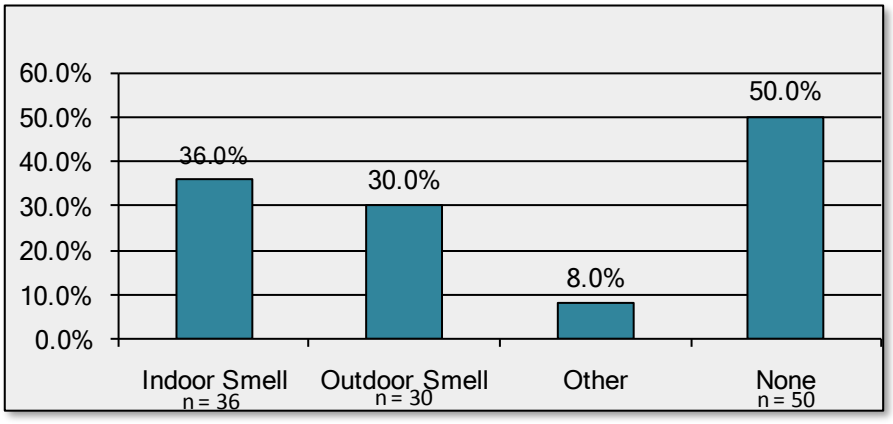


Figure 4.6 Sources of sensitivity to smell

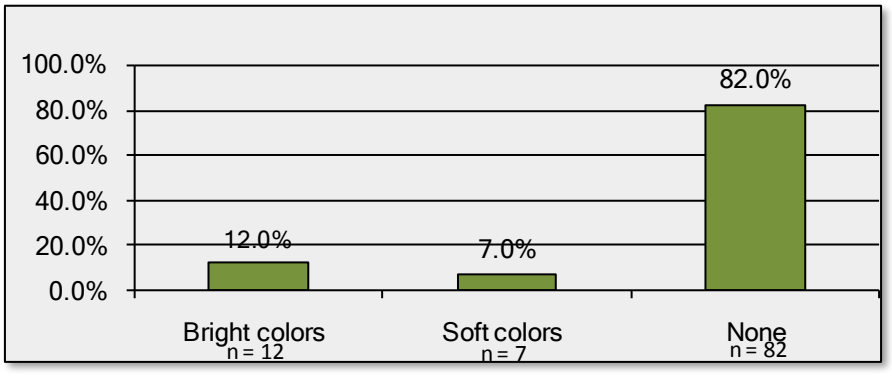


Figure 4.7 Sources of color sensitivity

4.2.5 Common autism-related Behaviors that Triggered Home Modifications

Families were asked to report the most prominent autism-related behaviors that affected their quality of life and led them to modify the physical environment of their homes. The lack of a sense of danger was the most common response, given by 53% of the respondents. Tantrums and repetitive behaviors came second, reported by 28% of the families, followed by social withdrawal and aggressiveness, which were reported by almost one fourth of the surveyed families (Figure 4.8).

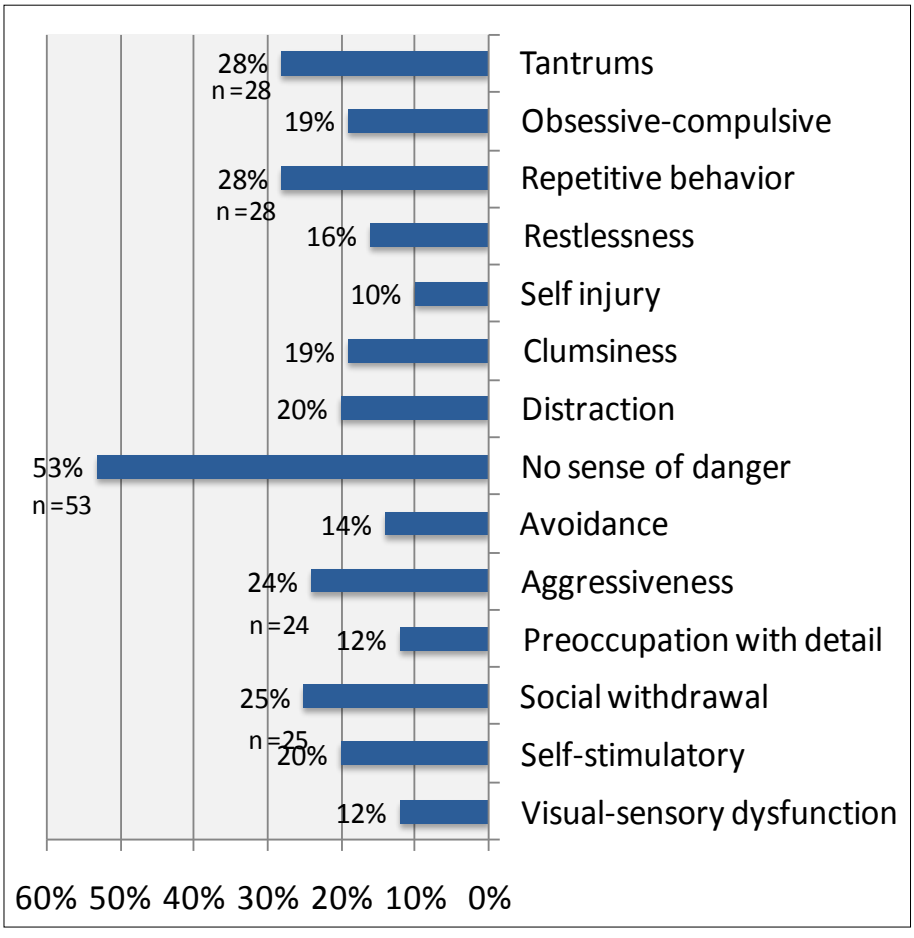


Figure 4.8 Common autism-related behaviors that triggered modifications

in the physical home environment

4.2.6 Common Challenges Faced by Family Members

The effects of autism reported on family members were considerable. A number of respondents were willing to share their personal experience and describe the challenges they faced as a result of having a child (or many children) with autism at home. They contributed 70 statements that described, in detail, their (a) psychological, (b) social, and (c) physical challenges. (Figure 4.9)

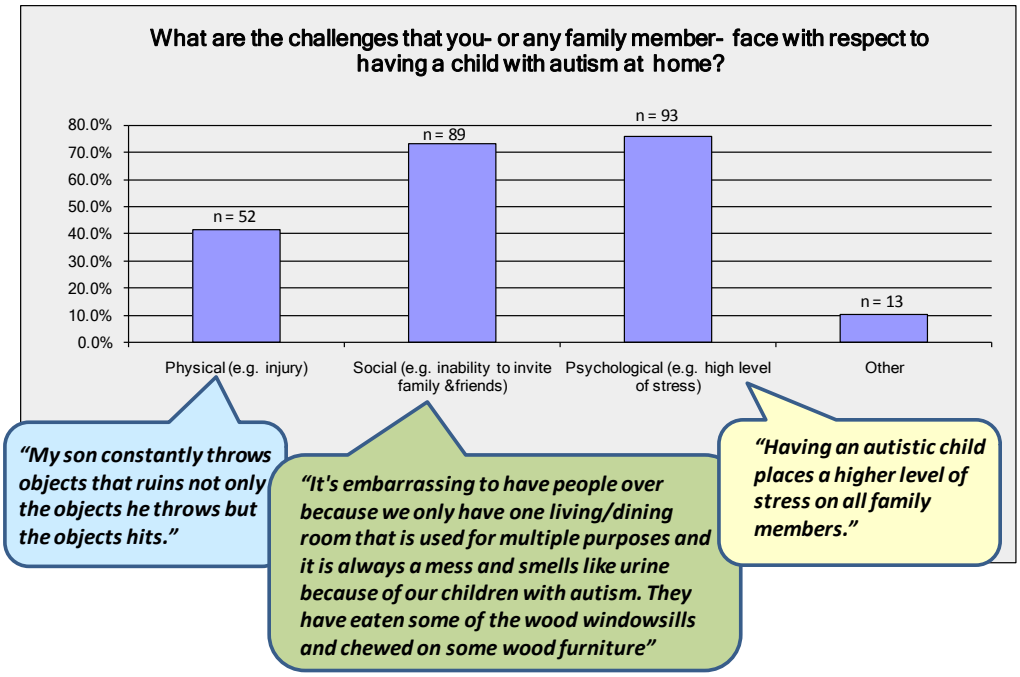


Figure 4.9 Challenges faced by family members

(a) Psychological challenges

The majority (76.2%, n = 93) of the respondents admitted to experiencing significant psychological and emotional setbacks as a result of living with a child on the spectrum. Autism imposed a high level of stress on all family members because of the negative social and physical consequences of autism-related behaviors, and the continuous effort to curtail the behaviors. The embarrassment from such behaviors exacerbated family stress:

> *It's embarrassing to have people over because we only have one living/dining room that is used for multiple purposes and it is always a mess and smells like urine because of our children with autism. They have eaten some of the wood windowsills and chewed on some wood furniture. Walls are dinged up because of their behaviors. It is very stressful for our family because it is a relatively small house and it has an open floor plan so our neurotypical children are always told to hush so as not to disturb our children with autism because noises can ramp them up and cause meltdowns.*

Siblings tended to feel neglected as parents have to devote their time to the child with autism.

> *Some days he requires more attention and we often feel our younger son is left out which is a problem because he's not less loved.*

Parents also reported a high level of anxiety due to: budget limitations; their inability to secure an acceptable living environment for all family members, and; the future of their children with autism:

> *Constantly worrying if we are "doing things right" or if we might be "causing more harm." Committing to dietary changes for one child can be difficult on a limited budget, and have to worry that the nutrition of the other child is still adequate. Feels like there is never enough time to keep the house in order.*

Some statements by the respondents revealed severe depression and unhappiness as *"... everything in life is hard."* A mother of two children with Asperger's syndrome commented:

> *Raising my twin sons has been the single hardest, most stressful act of my life. It exacts a heavy toll. I was deeply depressed for about two years, when the boys were 3-5, and even contemplated suicide*

Some respondents also noted that being a single mother exacerbates the psychological stress associated with having a child with autism.

(b) Social challenges

Almost 73% (n = 89) of the respondents experienced social difficulties as a result of having a child with autism at home. Feeling isolated from friends, relatives, and the community in general because of autism-related behaviors was a common complaint:

> *Sometimes we feel isolated when we cannot have people over for long period of time because of behavior or we cannot take our autistic daughter to certain events because we know it could set off an autistic tantrum*.

Autism also exacted a heavy toll on the marital relationship of the parents. Some respondents reported the decrease of happiness in marriage which led, in some cases, to divorce.

> *My marriage to the boy's father did not survive the stress, however, despite two different rounds of marriage counseling.*

Poor relationship with neighbors was also a commonly cited problem by the respondents. Neighbors, in most cases, were annoyed by the noise and "*... complained about loud screaming or pounding on the wall at night."* Some unsympathetic neighbors went even further, as described by one of the respondents:

> *Other parents in the neighborhood have never let their kids come to our house. Someone used to call the police for minor little things. The police quit responding to those calls after a while, because we never did anything wrong.*

Some mothers also reported that, because of the demands of their children with autism, they had to sacrifice their professional careers, which added to the stress:

> *I was unable to keep my job, even part-time, due to the demands at home, and what was extremely stressful to me as well; I was a manager with employees under me when the boys were born.*

(c) Physical challenges

Physical challenges were reported by only 42.6% (n = 52) of the respondents. Destruction of household items was a common complaint. Most of the items had to be kept out of the reach of their children with autism.

> *They were highly destructive, so I had to put every single trinket, memento, book, and loose object away. Their bedroom, living room, and kitchen were virtually bare*.

Physical injury associated with tantrums and meltdown of children with autism was another common problem:

> *… family members are subject to high levels of emotional stress by our autistic child or at time injuries to herself, siblings, and at times us as parents.*

Children with autism require round-the-clock care and attention so that parents can cope with their demands and keep them away from risk. The majority of the respondents (62%, n = 65) confirmed that they had to supervise their children with autism all the time. This contributed to a continuous feeling of exhaustion, as expressed by a parent: "… *he also doesn't sit still…. his*

meltdown … physically takes a toll on our household." The efforts exerted by the mothers to keep the home clean and healthy tended to be overwhelming, as described by a mother of an 11-year-old child with autism:

> *He's not toilet trained and pees all over the floor in the bathroom so it's hard even to keep the house from smelling like feces. When people come over, I have to clean his bathroom, which is beyond disgusting*.

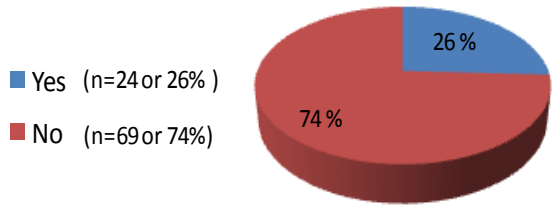


Figure 4.10 Moving to new home

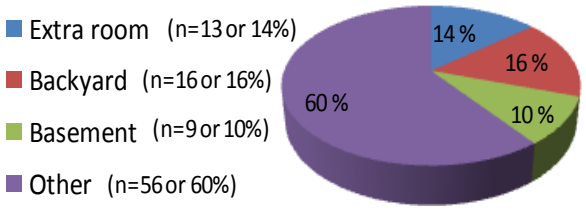


Figure 4.11 Adding space to existing home

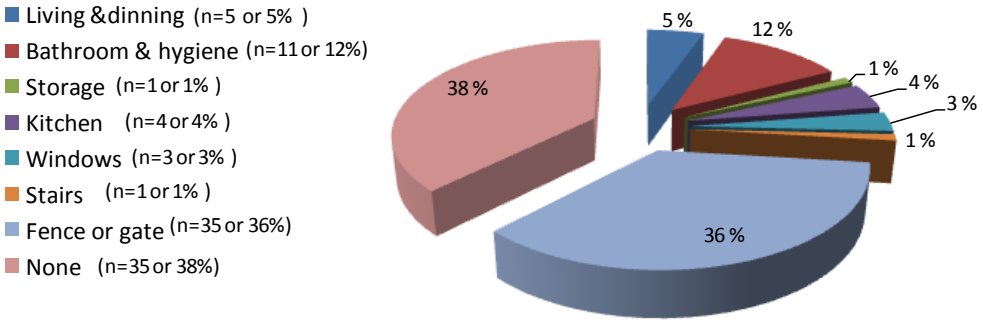


Figure 4.12 Modifications to existing spaces

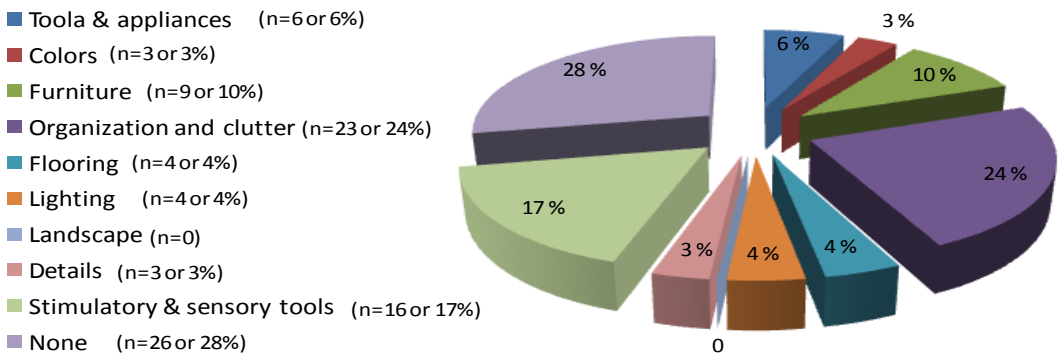


Figure 4.13 Changes to interiors

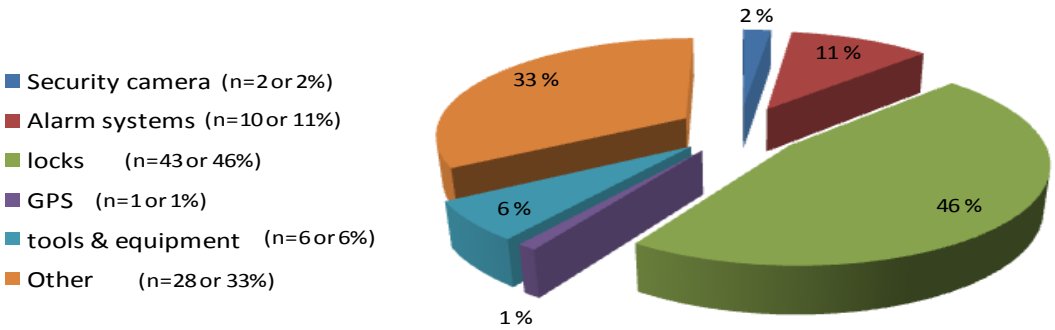


Figure 4.14 Technological tools

4.2.7 Physical Modifications to Home Environment to Alleviate Challenges

Families were asked to report the physical modifications they had introduced in their home environment to cope with the various challenges and to improve their quality of life. The majority of the respondents (81%, n = 78) indicated that the modifications were primarily targeted at the children with autism, while 15.5% (n = 15) indicated that the modifications were mainly to help the siblings. The type of modifications ranged from major, such as moving to another house, to minor such as installing locks on doors.

Moving to another place: Change of residence was reported by 27% (n = 26) of the respondents (Figure 4.10). The main reasons were to provide extra space to accommodate the needs of the child with autism and to give him/her more freedom to move around.

Adding extra space to the existing home: This modification was implemented by 40% (n = 38) of the respondents; 14% (n = 13) of the respondents reported adding an extra room, while the rest increased the space available in their basement or the backyard (Figure 4.11).

Modifications to existing spaces: The majority of respondents (35%, n = 35) added fences or gates (Figure 4.12). Bathrooms were the second most frequently modified space within the homes (12%, n = 11).

Changes to the interiors: Functional elements to reduce clutter and organize spaces (e.g., storage) were frequently added by the families (24%), followed by stimulatory and sensory tools (17%) as indicated in (Figure 4.13).

Technological tools: Because safety was a major concern, locks and alarm systems were installed by 67% (n = 66) of the respondents (Figure 4.14).

The estimated cost of modifications, as reported by 41% of the families, was less than $500, while 21% of the families reported a cost of over $3000.

4.2.8 Impact of Modifications on the Families' Quality of Life

The respondents were asked to answer an open-ended question on whether the modifications had helped in improving the quality of life of the household. While most of the

respondents replied in the affirmative, some expressed a few concerns. The following are the six major identified themes: less stress, freedom of movement, better personal space and privacy, reducing parental anxiety, continuation of daily routine, and efficiency will temporary.

***More safety, more time-out, less stress*:** The modifications helped reduce the numerous tasks that the parents had to perform to help their children with autism, while also giving them some relaxation time. They helped in minimizing the safety concerns and, therefore, contributed to lower stress levels among the parents. A mother of a 13-year-old girl with autism commented:

> *Without these modifications, my level of stress would be elevated with the multitude of things that I have to worry about daily in the struggle to fight for her rights, services, education, and dignity. At least with the changes I've made in the home, I feel more confident that she will be safe if I close my eyes to take a nap*.

Freedom of movement: Moving to a larger house or adding more space allowed the child with autism better opportunities to move around and engage in activities in a safe environment. This contributed to less negative behaviors and, therefore, fewer daily struggles for the family. A mother wrote about her experience after moving from an apartment to a townhouse:

> *There being more space to move about in the current home (includes a finished basement and space outside). We are able to give our child more freedom to explore and move around/bicycle safely.*

Better personal space and privacy for all family members: Re-arranging the house to provide a defined zone for the child with autism served to increase the privacy of all family members. Some mothers confirmed: *"… for sure he is no longer in our space all the time"; "… he now knows that he has specific areas around the house he can play in."*

Reducing parents' anxiety about the future: Modifications helped relieve some of the parents' anxiety related to the housing, safety, and independence of their children with autism as they approached adulthood; as describe by one participant:

> *I wish to build her an apartment in the back so that when the time comes for adult transition, she will have a place to learn independent living while still being safe inside our compound.*

Continuation of daily routine activities: Modifications enabled mothers to carry out their routine tasks at home while allowing them to supervise their children with autism. A mother describes the positive impact of removing the partition between the kitchen and living room: *"I feel better because now he can play near to me and I can see him while I am cooking."* Another parent appreciated the opportunity to enjoy a family gathering: *"We fenced the patio so we can enjoy outdoor lunch without him running around."*

***Effective but temporary*:** Respondents were aware that the modifications were temporary solutions and would have to be undertaken repeatedly to cope with the needs of their children as they grow up.

Findings of phase two, as described above, provided a wealth of information and broadened our understanding on the prevalence of challenges facing children with autism and their families in home environment as well as the modifications adapted to alleviate the challenges. The next section will explore the lived experience of families in their home environment and to which extent home modifications helped in improving their quality of life.

4.3 Findings of Phase Three

Based on the theory of therapeutic landscapes previously discussed, phase three examined the importance of place, particularly the home environment, for shaping health and healing among children with autism and their families. Narrative-diary interviews and field observations (n = 2) were conducted with three selected cases, each representing one of the three housing typologies: (1) house, (2) townhouse, and (3) apartment. The aim was to explore the in-depth lived experience of families with children with autism, while placing particular emphasis on understanding the daily challenges they face in their home environment. Further, this phase explores the modifications the families made to their home environment, as well as how the modifications have contributed to improving their quality of life.

4.3.1 Mathew's Story

4.3.1.1 Child and Family Profile

Mathew is a five-year-old boy diagnosed with pervasive developmental disorder (PDD-NOS), a mild form of autism. Although he currently lives with both parents, he is unaware that he is soon going to be living with one parent at a time. According to his mother, Sandra, she and her husband are now separated and will soon be filing for a divorce. The father is working and supporting his son, mostly financially, while the mother, who cannot work because of her son's needs, is clearly the primary caregiver in the household. At first, Mathew looks just like a normal child. He is verbal and goes to the neighborhood's mainstream school with no special considerations beyond taking an extra language class, because English is not his first language.

However, since he was three, his grandmother immediately noticed that he was not a typical child. He was late in everything especially talking:"*My mom told me he has some problems. Go to the doctor*." He then got his formal diagnosis, and the mother is clearly struggling not only to help her child but also to accept the fact that she will deal with it mostly as a single mother.

4.3.1.2 Neighborhood Profile

Postal codes were used to extract the census tracts representing the neighborhoods of all families interviewed in this phase. All data were drawn from Statistics Canada 2011 census and included variables chosen based on their usefulness in understanding the socioeconomic characteristics of each family. Socioeconomic factors are increasingly being considered as major determinants of many aspects of health and causes of health inequities (Odoi et al 2005).

Mathew's home is located in West Oak Trails Neighborhood, South Oakville, Ontario. By comparing the following socioeconomic data, it is noted that the median household income and the unemployment rate for this neighborhood is higher than of the City of Oakville. While the average family size is slightly larger, it is noticed that the percentage of population (15+) and the median value of dwellings is lower than Oakville.

Variable	Characteristics	West Oak Trails	City of Oakville
Population	Population in 2011	4,621	182,520
Age characteristics	% of the population aged 15 and over	72.8%	80.4%
Marital status	Married (and not separated) Single (never legally married)	62.7% 21.5%	57.8% 26.1%
Family characteristics	Average # of persons per family Average # of children per family	3.4 1.5	3.2 1.3
Dwelling characteristics	Total # of occupied private dwelling	1,360	62,410

	# of detached houses (Most common housing typology) Average # of rooms per dwelling %Owners %Renters Median value of dwellings ($)	1,025 7.5 92.9 7.3 480,173 (93.9% of Oakville)	39,455 7.5 83.8 16.2 510,886
Labour force status	Unemployment rate (15+)	9	7
Income	Median household income ($)	112,342	101,713

Table (4.3) Socioeconomic profile of West Oak Trails Neighborhood. Source: Statistics Canada.2011 Census Profiles

4.3.1.3 Housing Profile

Mathew and his family live in a spacious, two-story house (Figure 4.14). Their house consists of three bedrooms and an unfinished basement. Although he has his own bedroom, his toys are kept all over the house, particularly in the kitchen and the living room. Since the basement is unfinished, he usually receives his therapy on the dining room table.

Figure 4.15 Mathew's neighborhood

4.3.1.4 Challenging Autism-related Behaviors

Sensory

Mathew is highly sensitive toward light. According to Sandra, this includes all light, including sunlight. He is also sensitive toward sound, particularly loud noises. He does not seem bothered by noises outside, but he usually asks about it or where is it coming from.

Behavior

Sandra says that Mathew's two most challenging behaviors are hyperactivity and distractibility, which makes it hard for him to follow instructions. He constantly wants to move and play.

> *All the time he jumps. When its lunchtime, he doesn't keep quiet for two minutes … his leg, all the time is moving. I need to explain to him, when its lunchtime he needs to sit.*

Mathew's constant movement makes his mother fear for his safety: *"…the stove is not electric. It is gas. For that, I am scared. It's more hot and strong."*

When Mathew was three, he once opened the door and left the home. He also loves to play with water.

> *When he goes to the bathroom ... wants to wash his hands … I can listen, he'll take more time because I know he likes to play.*

Social and Communication

Mathew is verbal, sociable, and very friendly. Although he gets few birthday invitations from school, which he enjoys a lot, he has never actually had friends come over to his house:

> *I'm going to friends, but they don't have kids or their kids are older than mine.*

Although Mathew likes to go out to visit people, his mother wishes to invite people with

children to come over to their house to socialize with Mathew:

> *Sometimes [pause] I don't have an opportunity for doing some relations.*

Otherwise, he usually goes to the swimming pool with his father one day and his mother another. He goes to play outside in the park with either of his parents but not together as a family.

Mathew is more attached to his mother (Sandra) because, when he was younger, they stayed in their home country together at his grandmother's house while his father was working in Canada. Now he still likes to be around his mother. He will wake up at 3 a.m. and ask her to come and sleep by his side.

> *He doesn't like to be alone … less than one minute, he calls me, "Mommy, mommy." For example, I stay in the bathroom and I need to answer. 'I'm in the bathroom,' and he'll open the door*.

4.3.1.5 Autism-related Family Challenges

Physical

Sandra described the physical effort of taking care of her son as "hard work." She is always tired: "*All the time. Honestly, very."*

When Mathew goes to school, she spends her time drawing and cutting visual materials to aid him in therapy. After he comes home, it is usually cooking, homework, and some playtime with her and his father, who arrives late from work. Mathew only gets therapy three times a week; on the other days, his mother is his therapist. She tries to learn constantly about strategies to help her child. She complained of the financial burden of Mathew's therapy. "*He takes home therapy … but it's too expensive … all of them are very expensive. Very expensive … I*

can't continue paying."

Social

Sandra and her husband are separated, but they were still living together in the same house at the time of the interviews. She tries to hide the truth from her son so as not to affect him. They never go out together as a family, but would take Mathew to the park or swimming on separate days. Sandra is struggling to make relationships with others. Because they are new to the area, they do not have many friends. Her main goal now is to know people with children, particularly, with those the same age as her son. Sandra mentioned that Mathew embarrasses her when he says inappropriate comments in front of people: "*At a friend's house … we eat different dishes that Mathew doesn't know and [he] asks me, 'Mommy, what is that?*' *For example, it's potato. He eats, 'EW'.*"

Psychological

Despite having a son with a relatively mild symptoms, Sandra seemed to be the comparatively most stressed mother among the three cases I interviewed. I truly believe that the lack of family support, particularly from her husband, is affecting her deeply and making her "depressed." Sandra spends most of her time doing things for her son, while the father is mostly very busy at work:"…h*e works and pays … he doesn't have time."* Despite her efforts, she gets constant blame from her husband that she is not doing her best to help their son: "…h*e thinks I spend all the time on the couch and that's it. No. That's not true."*

Moreover, Sandra decided to leave her home country and the support she was receiving from her parents to come to Canada. She truly believes that it's the right place for raising her son. Her husband is putting more pressure on her because he does not think it was the right decision:

> *I want to live here because his development is better than my country. But he doesn't understand me. It's another pressure for me because he is pushing me and I feel guilty.*

In addition, I have realized that Sandra keeps blaming herself for the lack of social relationships in her son's life:"…*I know it's my fault because I don't know … sometimes; I don't have opportunity for doing some relations."* She also worries about people judging her son: "…*I don't like them to look at my son like he's a bad boy."*

Sandra is also worried about not working, and she believes working could be a way to help her child.

> *I want to work to give my son everything he needs … I need to improve my English and I want to study … I can't work in the afternoon for my boy. I can't leave my boy and go to work because I feel so bad.*

4.3.1.6 Physical Home Modifications and the Family's Quality of Life

a) Modifications related to the ability to move:

Modification	Significance
1. Removing the partition between the living room and the dining room	Providing more space for movement (Figure 4.16)
2. Increasing the outdoor deck area	Providing room for running and playing (Figure 4.17)

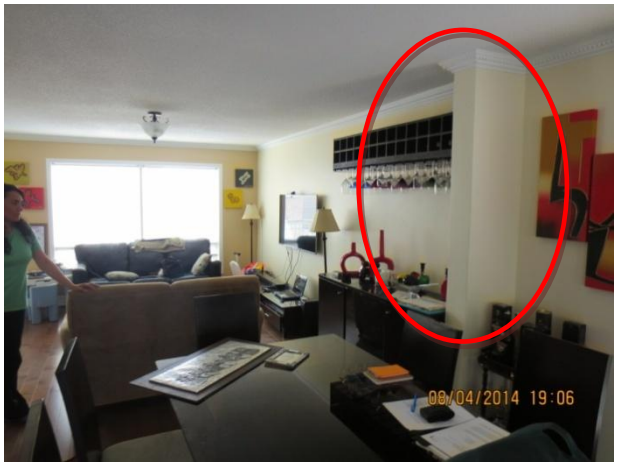


Figure 4.16 Partition removed to allow for more space

Figure 4.17 Deck size increased for more room

b) Safety-related modifications:

Modification	Significance
1. Use of strong materials to build the larger deck area	Durability especially with having a hyperactive child
2. Adding a fence around the deck	Preventing escape (Figure 4.17)

c) Sensory and behavior-related modifications:

Modification	Significance
1. Shifting the therapy area from the dining room to the living room	Minimizing distractions
2. Removing all carpets	Preventing possible allergic reactions

3. Removing the partition between the kitchen and the living room	Ensuring constant supervision
4. Installing black curtains in Mathew's bedroom	Addressing Mathew's light sensitivity (Figure 4.18)
5. Covering the table lamp in Mathew's bedroom with a dark cloth	Same as above
6. Using symbols and visuals	To aid in communication (Figure 4.19)

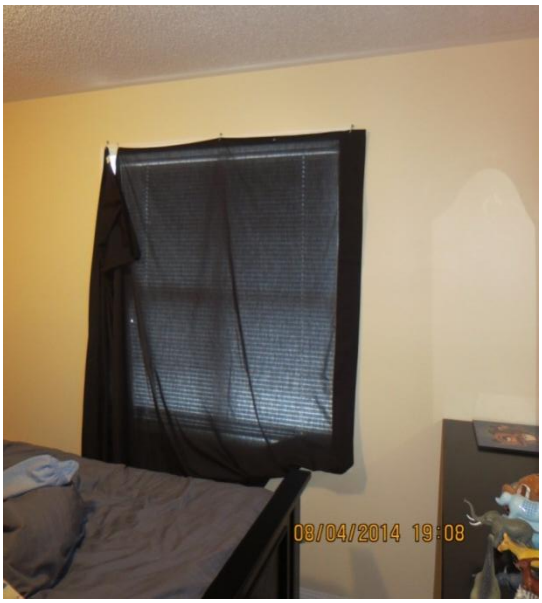


Figure 4.18 Use of dark curtains in Mathew's bedroom to help with his light sensory issues

Figure 4.19 Mathew's family uses visuals that represent activities

d) Space organization-related modifications:

Modification	Significance
1. Transforming one corner of the living room to a play area	Mathew hates being away from his mother (Figure 4.20)
2. Adding a cupboard in the kitchen	It contains accessible materials for continuous therapy by the mother
3. Limiting the amount of furniture at home and keeping decor simple	Increasing the space as much as possible to accommodate the hyperactivity of Mathew

Figure 4.20 Mathew's toys and learning materials in the family's living room

Sandra is happy with the modifications she has made to her house:"*At home, he has everything he and I need."* She feels safe and she does not need to worry about her son, although she would not mind an even larger house. Moreover, she hopes to be able to

complete the unfinished basement where her son could play and have his therapy:

I think it's the best place ... he can get everything.

Since her son is very active and loves to jump, she wishes to have a space to get him a trampoline. Because of the divorce impending, Sandra and her son might move to an apartment soon. She will not be happy if this happens, but insists that a big space will always be her first priority. She also added that if she moves, furniture will also be kept to a minimum. Her priority in a new home is an open kitchen, where she would be able to supervise her son. She also prefers a condominium with a swimming pool because of Mathew's hyperactivity and passion toward water.

Despite the fact that Sandra has a son with a mild diagnosis on the Autism spectrum; she is clearly struggling to cope. Living in a spacious house is not helping her much to face the challenges of raising her high functioning son. However being separated and heading toward a divorce is the real challenge to her. The constant self blame for her son's limited social relationships and the continuous fear for his future are challenges that exceed the physical challenges she's experiencing everyday.

4.3.2 Massimo's Story

4.3.2.1 Child and Family Profile

Massimo is a nine-year old boy with severe autism. He is living with his parents and his 11-year-old brother in their family home. Massimo is nonverbal, and he shows most of the known characteristics of autism. He goes to a special education school every day for a few

hours. The family is well off. They are supported financially by the father, while the mother, Sonia, who wished to be in a career, chooses to stay at home to support and care for Massimo. Massimo is lucky to be part of a very close, loving, and supportive family.

4.3.2.2 Neighborhood Profile

Massimo's home is located in the Mineola community in south-east Mississauga, Ontario. By looking at the following table, which represents the socioeconomic profile of Mineola, it is clear that the median value of dwellings and the median household total income of the neighborhood is much higher than that of the City of Mississauga. While the unemployment rate (15+) of Mineola is much lower than Mississauga, the percentage of the population (15+) and the average number of persons per family is almost similar.

Variable	Characteristics	Total Mineola	Total Mississauga
Population	Population in 2011	3,683	713,443
Age characteristics	% of the population aged 15 and over	82.8	82.0
Marital status	Married (and not separated) Single (never legally married)	56.4% 25.1%	54.4% 29.5%
Family characteristics	Average # of persons per family Average # of children per family	3.2 1.1	3.2 1.3
Dwelling characteristics	Total # of occupied private dwellings # of detached houses (Most common housing typology) Average # of rooms per dwelling %Owners %Renters Median value of dwellings ($)	1,325 1,105 7.7 92.8 7.2 539,259 (34% higher than Mississauga)	234,585 91,690 6.3 74.9 25.1 401,175
Labour force status	Unemployment rate (15+)	6.3	8.7
Income	Median household total income ($)	102,082	75,556

Table (4.4) Socioeconomic profile of Menola. Source: Statistics Canada.2011 Census Profiles

4.3.2.3 Housing Profile

The family lives in a townhouse (Figure 4.21) overlooking a small children's park, shared with the similar, surrounding townhouses in the compound. The family moved to this townhouse two years ago, seeking a safer space. The two-story townhouse has four bedrooms, bathrooms, a kitchen, and a spacious basement. It also has a backyard, which the family frequently uses for play and gatherings.

Figure 4.21 Massimo's family's townhouse

4.3.2.4 Autism-related Characteristics and Challenging Behaviors

Sensory

Massimo is highly sensitive to sounds, especially loud and deep ones, both inside and outside of the home, such as the sound of appliances and school buses. His mother (Sonia) stated:

I need to warn him when I switch on the vacuum … if he goes on the school bus

when there is a field trip, every time there is a bus, he covers his ears.

On the other hand, he likes to hear loud music. His mother thinks that it is all about being "*in charge*" or being able to "*control*" things. One of the biggest concerns to the family is that he is easily distracted:

He's very visually distracted, so his bedroom, he would just look outside forever.

Massimo's mother realized that dimming the lights helps him to calm down:

It's like relaxing for him when we switch off the light or just dimming them.

When it comes to temperature, Massimo hates it when it is too humid or too warm.

Behavior

Massimo likes to move, and he has some hyperactivity. He loves the computer and going to the basement to play with the trampoline. His mother stated that *"He likes to run around and play".* He also likes to literally eat nonedible things, such as toys. He has tantrums and head banging moments "*when he is stressed out or when he doesn't want to do something, he hurts himself".* According to the mother, another challenging behavior is having him follow instructions when he does not want to:"…i*t's harder now, growing up, it's harder*."

Massimo's behavior makes his mother concerned over his safety. For example, he likes to play with anything including medicines and detergents:"…h*e likes to squeeze the detergent and play with the sponge*." He particularly loves playing with water, especially in the kitchen sink and the toilet. Massimo has no sense of danger. That is why the mother says that she needs to "*check*" on him very often, especially when outside*:*

When we go to a park, for example, we need to be sure to watch on him, mostly because

we don't want him to run in the street.

Massimo loves to stay in the living room because he enjoys looking out of the windows, as his mother mentioned:"…*looking out the windows … mostly when it's raining or snowing or there is wind."*

Social and Communication

Massimo is nonverbal. He uses an iPad equipped with a communication program which has symbols and pictures that he can press on and it "talks":

He's not able to communicate if he has something that he's dealing with that stresses him or something that upsets him.

Despite being nonverbal, he is a very sweet boy; that is, according to his mother; is very accepted by others:

He doesn't really show huge behaviors against other people.

Nevertheless, he does not initiate interaction, more often waiting for others to approach him:

If he tries to initiate, usually it's not in an appropriate way. He jumps in front of people or goes too close to people. He still needs to learn how to approach people in a more appropriate way … we had kind of weird episodes, like him going and sitting on the lap of someone at the airport that was a complete stranger … or, he jumps in a puddle and the person was just there, so he got all wet.

His "patient" brother plays with him a lot, but he prefers to play with his own friends and have them come over.

According to the mother, the hardest part is dinnertime, when he usually stands during dinner and leaves the table. Visiting others is not an easy thing to do:

We prefer always having people over because we are calmer here, so we can enjoy our friends and he can go anywhere because we arrange things in a way, instead of a different

house. When he's not familiar with the house, he likes to explore and touch everything.

Although Massimo likes to be around his family, he still likes to spend time alone.

He comes and then he goes away. He also needs lots of time by himself … he can't stay for a long time with some people ... he also likes to get his breaks away.

Imagination

Massimo has a short attention span, which, according to his mother, prohibits him from participating in any kind of a team sport. Although he swims, it is only considered part of his therapy:

He wouldn't follow the instructions.

Massimo has some dysfunction in play and imagination skills. For example, when it is wintertime and he goes out to play at school, he does not play with snow like other children, instead, he likes to "eat" the snow. According to Sonia:

He goes under the television bench and collects dust there and plays with that.

4.3.2.5 Autism-related Family Challenges

Physical

Massimo's family decided to bear the financial burden of buying a new house that would also accommodate their son's needs; they purchased their townhouse two years ago. According to Sonia, Massimo is a "*mess maker*," that is why she says that there is a lot of physical work at home, particularly cleaning up:

I have to clean a lot around the house and wash a lot.

She also thinks that her workload is increasing because Massimo is getting physically stronger as he is growing up.

I can't move him like when he was younger because he's a stronger child.

Massimo struggles to eat by himself, so his mother helps him by cutting his food for him.

He still needs some help when he eats. Well, he can eat by himself, but, as I said, he's a mess maker.

He also wakes up a lot during the night asking for his mother, so this adds to more physical burden to her.

It's around 2 a.m., he comes and calls me, and so I go to his bedroom and stay there with him.

The family tries to avoid parks because Massimo loves to play with wood chips and throw them, which could cause injuries: "…*It can be kind of annoying for other kids, young kids."*

According to Sonia, Massimo sometimes goes through very strong "*chewing phases*," which result in physical damage, particularly to his brother's and visitors' belongings. For example, he loves to chew nonedible things, such as toys, headphones, and even plants*:*

My oldest son, all his super heroes were without fingers and toes.

Although it does not happen very often, Massimo sometimes tries to hit his parents and brother:"*He was hitting us when we were saying no … sometimes hard."*

Social

Luckily, Massimo is a member of a very close family that tries constantly to do things together; for example, enjoying a family dinner together each day. However, things usually do not work the way they want them to: "*He goes back and forth, so he's not staying with us for all the time even if we tried. "*

Even simple activities, such as watching the TV together, are nearly impossible:"*It's not that I can sit and watch a movie with my family for the whole time."* In addition, they try to avoid places that they think will not work for him:"*We can't go with him to a regular movie theater because it wouldn't be possible."*

Sonia is sad and aware that Massimo's brother is not getting enough of their time and care. She would love to see him regularly playing soccer:

> *Not every time can I go, and, if I go, I'm always running after my other child and not really paying attention ... he understands that my child drains a lot of energy from us. Of course, he's a child too.*

Massimo's family complains of the inability to visit anyone, which is why they prefer to have family and friends come to their house instead: "*We can enjoy our friends, and he can go everywhere.*" They also try to explain their son's behaviors to their visitors; otherwise, they would have to deal with embarrassing situations. Sonia explained that adults can understand such behaviors, but it is always harder to explain it to children. She mentioned some embarrassing situations with neighbors. For example, she could not stop her son from trying regularly to go their neighbor's swimming pool:

> *During the summer he was putting up his above-the-ground pool, which was always a concern because my child loves water. He was just going there and trying to go inside.*

She also received some complaints because Massimo would jump and make "high-pitched sounds." Finally, when I asked Sonia what she misses about not being in a job, one of the first things she mentioned was the social life:"*I'm lucky enough – let's say – that I can stay at home. I worked before. I miss a lot of the social part."*

Psychological

The stress that accompanies raising a child with autism is more difficult for Massimo's family to deal when compare with the physical or the social challenges:

> *I think its more tension related to being tired … there are moments of tension in the family…. I think it's kind of a stressful life.*

Because Massimo lacks a sense of danger, Sonia is particularly concerned about his safety; particularly when he is outside the home:

> *Sometimes it's more stressful because it's not a fenced park and very close, there is the inside street. It's not a public street, but still there are cars moving.*

When they happen to be in someone's place, she thinks every second about what he is doing:

> *It's not really enjoyable, because we need to think where he is, what he's doing, and what he's going to do.*

Massimo's brother suffered as well, especially when he was younger and could not understand his brother's behavior of eating his toys.

> *It wasn't even so easy for him understanding why he was doing that and why he was ruining his toys … he was annoyed and was complaining about it*.

Before moving to the new townhouse, Massimo's brother had to share his bedroom

with him. Sonia revealed that he could not at that time, sleep well nor invite his friends for a sleepover; something he really wanted to do. Massimo's brother is clearly psychologically stressed as well:

> *We try to spend time with my older son, but I think he had to adapt himself too … he learned how to wait ... because you can't be everywhere … I wouldn't say he has a regular life, like a regular brother.*

Sonia believes that there are more things to think about now than if they were just a regular family:"*When I see other families, I think, for them, everything is easier than for us."* However, she is certain that the reason that she is able to take all this stress is the strong support she is continuously getting from her husband:"..*If I was a single mom, for sure, that would be much stressful."*

According to Sonia's husband, they are well off and there is no urgency for her to work to provide money sustaining the family's needs. However, Sonia stated that she is strongly missing the feeling of self-esteem accompanied with having her own career:

> *I miss also being successful … it's like building something for yourself … my husband doesn't like when I say that, but you have your own money.*

The following pages will explain the modifications adopted by Massimo's family in an effort to alleviate some of their daily challenges previously discussed above.

4.3.2.6 Physical Home Modifications and the Family's Quality of Life

a) Modifications related to the ability to move:

Modification	Significance
1. Moving to a new home that has a large basement	Massimo can play freely and have therapy in a dedicated space with all his toys and trampoline See (Figure 4.22)
2. Building a large fenced deck	The whole family can enjoy outdoors without leaving home See (Figure 4.23)
3. Adding a gate to access the basement	Accessing the basement is restricted by a gate fearing Massimo's safety

Figure 4.22 Basement is dedicated as a play and therapy space

Figure 4.23 Large outdoor fenced deck

b) ***Safety-related modifications***:

Modification	Significance
1. Fencing the deck outside	Making sure that Massimo does not run away
2. Removing the partition between the kitchen and the living room	Allowing the parents, particularly the mother to constantly supervise her son
3. Moving everything that is considered dangerous, such as medicines and detergents, to an unreachable place for example, up on top of the refrigerator and shelves	Addressing Massimo's behavior of eating non edible things (Figure 4.24)
4. Adding locks to unsafe areas and spaces at home, such as the laundry room, washrooms, and windows.	Addressing Massimo's passion for water and no sense of danger (Figure 4.25)
5. Insuring that the main door is closed at all times	Addressing no sense of danger and running away
6. Choosing a nontoxic material to cover Massimo's mattress	Massimo is not toilet trained yet. His love of chewing and eating things makes it essential to choose materials that are safe to him.
7. Placing covers on electrical plugs	Addressing the no sense of danger behavior where he can touch anything
8. Removing all plants and decorations and placing them in an unreachable place	The behavior of eating nonedible things such as plants
9. Covering the stovetop	Preventing Massimo from touching hot surfaces

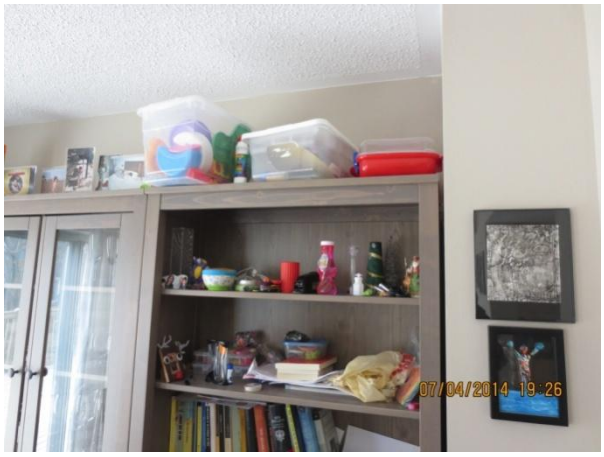


Figure 4.24 Dangerous materials placed in an unreachable place

Figure 4.25 Installing locks that are out of reach in the laundry and washrooms

c) ***Sensory and behavior-related modifications:***

Modification	Significance
1. Shifting the therapy area to the basement	Minimizing visual distractibility from looking outside through the windows
2. Having his "own" bedroom	Massimo can go to his bedroom whenever he is bothered or stressed
3. Replacing the regular light in Massimo's bedroom with one that has protection	Minimizing sensory sensitivity toward bright light
4. Dimming the lights in the house	Helping him relax and calm down
5. Shutting down the heating fan	Avoiding the sensitivity from noise coming from it
6. Changing the interior wall paint to a lighter color	Helping him relax
7. Removing the carpets	Installing cleanable flooring to help address the constant spilling accidents

	(Figure 4.26)
8. Ignoring fancy décor and buying simple and washable furniture for the sofas and the chairs' covers	Helping the mother in addressing spilling accidents (Figure 4.26)

Figure 4.26 Cleanable floors and washable sofas

d) Space organization-related modifications:

Modification	Significance
1. Removing nonessential furniture from Massimo's bedroom, keeping decor simple, with just a bed, chest of drawers, and a built-in closet	Addressing his safety in addition to minimizing the chances of messiness (Figure 4.27)

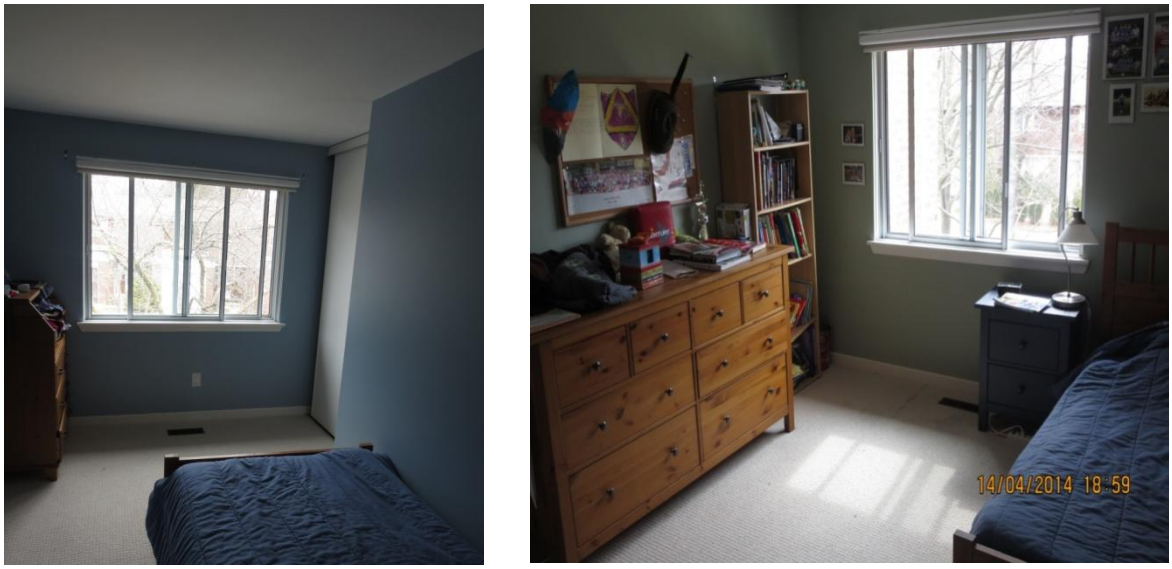


Figure 4.27 Massimo's room is kept simple, in comparison with his brother's room, which looks like a typical boy's room

Sonia is very satisfied with her townhouse, and she believes that the above-mentioned modifications have dramatically improved her family's quality of life:"…*I feel less stressed if I stay here … it's a place, for sure, where you know can be in control and can relax."*

She cannot imagine living in an apartment though:

> *It would be more claustrophobic … I really appreciate the idea we are here and not in an apartment … he has the space to run ...if my other son has friends and Massimo is bothered by them … he can go somewhere*.

Having a separate area for Massimo's therapy, the basement, has definitely helped her child (see Figure 4.22). For example, she believes that the corner with the table and with the visuals on the walls is the ideal setup (see (Figure 4.28). Sonia revealed that the "symbolic" aspect of the home environment represents the place of work for her family, particularly, Massimo:

When he sits there, its work time. I think it's important making that connection

Figure 4.28 Using visuals on the walls of the basement to make it easier to understand daily activities

However, Sonia still wants few additional modifications, such as adding more shelves or closets with keys so she can put more things away from her son. She also wants something to block his access to higher places because he is growing taller. Other modifications she wishes to do but, for the time being cannot include: moving to a separate house with distant neighbors, and being able to decorate her townhouse with all the plants and flowers she loves.

Massimo's family is continuously implementing modifications to accommodate his needs. They believe that this doesn't only help him but also them by putting their minds in peace concerning their son's safety. They believe that being a close family is what is keeping them strong in facing all the challenges of raising a child with severe autism.

4.3.3 Shushmin's Story

4.3.3.1 Child and Family Profile

Shushmin is an 11-year-old boy who has mild autism, with a delay in speech. His father died a couple of years ago, leaving him with his mother, Rupa, and his eight-year-old sister. He attends a mainstream school with special settings and considerations. His daily activities are very scheduled; he gets up, brushes his teeth, eats, and goes to school. When he comes home, he has lunch, then a little bit of creative time, and then he sleeps. Rupa works daily as a nurse in the Canadian Red Cross, but she tries to avoid working in the evenings in order to meet her children's needs, especially after losing her husband. His younger sister is a "*second mother*" to him when Rupa is away.

4.3.3.2 Neighborhood's Profile

Shushman's home is located in the Hurrontario community in central Mississauga, Ontario. The following data collected in the 2011 Census of Canada and National Household Survey highlights some of the socioeconomic variables for this neighborhood. It is noted that the average number of rooms per dwelling, median value of dwellings, and the median household income is much lower than that of the City of Mississauga, despite the similar average family size.

Variable	Characteristics	Total Hurrontario	Total Mississauga
Population	Population in 2011	7,003	713,443
Age characteristics	% of the population aged 15 and over	85.3	82.0
Marital status	Married (and not separated) Single (never legally married)	52.3% 30.7%	54.4% 29.5%;."

Family characteristics	Average # of persons per family Average # of children per family	2.9 1.1	3.2 1.3
Dwelling characteristics	Total # of occupied private dwellings # of detached houses (Most common housing typology) Average # of rooms per dwelling %Owners %Renters Median value of dwellings ($)	2,730 1,595 5.1 73.6 26.2 300,049 (74.8% of Mississauga)	234,585 91,690 6.3 74.9 25.1 401,175
Labour force status	Unemployment rate (15+)	9	8.7
Income	Median household total income ($)	66,620	75,556

Table (4.5) Socioeconomic profile of Hurrontario community. Source: Statistics Canada.2011 Census Profiles

4.3.3.3 Housing Profile

The family has lived for eight years in a relatively small, two-bedroom apartment (Figure 4.29). For this reason, Shushmin does not have his own bedroom; he sleeps next to his mother. The living room is his own place, where he spends most of his time.

Figure 4.29 Shushmin's family apartment in the heart of Mississauga

4.3.3.4 Challenging Autism-related Behaviors

Sensory

Shushmin does not like loud noises, such as the TV or stereo.

> *Even if it's [a] horn … any kind of loud noise, he doesn't like … he will shut his ears and lay down … if I lay down, he's okay.*

This also applies to noise outside: "*…If I go out and somebody's like screaming, then he will say, 'Mommy no loud,' that's it."*

Behavior

One of Shushmin's most challenging behaviors is his lack of focus.

> *When we do homework, we have to really make him concentrate … the problem is making him concentrate and sit down.* He is also moody. *If he wants, he will do right away … if he doesn't like anything, he will keep quiet and he will not do anything.*

Rupa revealed that Shushmin does not like to be forced into anything. If forced, his behavior gets worse*:"…he will understand by himself, but don't force him. Give him some time."*He also likes to explore new places. According to Rupa: "*…If it's a new house, I'm really worried."*

Although Shushmin has a sense of danger, Rupa said that she could not leave him unattended or permit him to go out from the apartment by himself:

> *All the time they're asking, 'Mommy, can we go downstairs for park?' But, every time I have to go with them. I cannot leave them alone.*

She also fears that he will lock himself inside the washroom since she does not have the keys and the apartment does not provide the keys.

Social and Communication

Shushmin's communication skills have improved with age.

> *Before, we had to really put our effort to make him understand … he used to be really noncooperative, but nowadays he can express more. We're getting what his problem [is], and we try to solve that one.*

Rupa says that her son is very sociable: "*My son has more friends than my friends … everybody loves him, and he is kind of very, very, you know, very lovable son … I am very proud of him.*"

However, she cannot invite any friends to visit in their apartment because of the lack of space:

> *I am working outside … I have to take them out … I cannot call anybody … because only two bedrooms, and one is very small, so I cannot leave kids in that room and … I had to make my report.*

Shushmin's sister is also a great supporter to him. She plays with him and helps him with his homework:

> *We give him priority in everything … sometimes like … leave your homework, help him first, and then do yours.*

However, Rupa added that being of different sexes is causing some problems:

> *My daughter wants to play with dolls; my son wants to play with cars … sometimes my son gets stressed from that … like okay, 'Nobody wants to play with me.' And then I have to sacrifice some of my time … just to give a little bit, you know, company.*

4.3.3.5 Autism-related Family Challenges

Physical

After the death of Rupa's husband, she found herself forced to work to provide for her children's needs. "*I work. I'm so tired*." She works in the mornings and is only 'on call' in the

evenings in order to be there for her children. She is carrying the entire financial burden that comes with raising two kids, and especially one with autism:

> *My son loves music … I want to put him in a music class, but I can't afford to … because these are expensive*.

Social

Rupa does not remember the last time they had dinner together as a family:

> *Before, when my husband was there, we're, we never missed our dinner. Like we always sit together and enjoy our dinner … sharing each other. But, nowadays, no … I have to make them first … then like my turn comes and I'm finishing my dinner in a hurry … so yeah, dinnertime missing, story time missing … what they did in school … what they like … their feelings.*

She also finds it very hard to invite friends to her small apartment:"…*I cannot call anybody … I cannot leave kids in that room, and … I'm working outside. I can't do that."*

Psychological

Life turned upside down after the death of Rupa's husband. According to her, he used to take care of half of the problems:""*You go out; I will take care of him. Don't worry.*" Now she finds it very stressful to deal with everything alone:"

> *Since I lost my husband, life became horrible to me. Like I want to give them [her children] more time, but I cannot … I need some break; which I'm not affording to.*

According to Rupa, Shushmin's younger sister is under no less pressure. She shares a bedroom with her brother, something she finds it very difficult:"

> *She wants actually, one separate, but I try to make her understand, it's not possible right now. So you have to actually share with your brother.*

Despite doing all she can, Rupa cannot stop feeling guilty toward her kids:"*I want to sit and*

read with my son, but I don't have time."

4.3.3.6 Physical Home Modifications and its Impact on the Family's Quality of Life

a) Safety-related modifications:

Modification	Significance
1. Putting locks on windows	Fearing for the Shushman's safety

b) ***Sensory and behavior-related modifications:***

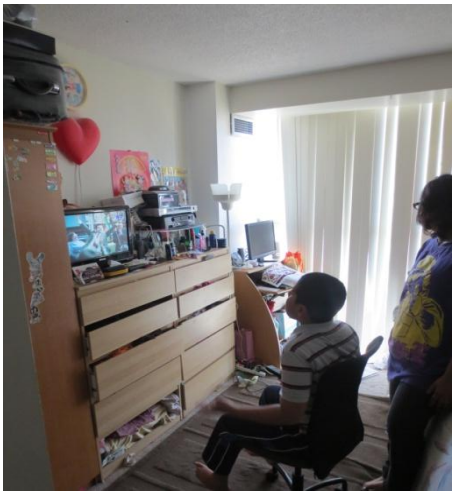
Modification	Significance
1. Shifting the study area to the dining room	Keeping away from the TV, to minimize distractions and increase supervision (Figure 4.30)

Figure 4.30 Dining table used as a study area; it is placed away from the TV and in front of the kitchen, to ensure constant supervision

Space organization-related modifications:

Modification	Significance
1. Transforming one corner of the living room into a play area	Making up for the lack of space- no separate bedroom for each child (Figure 4.31)
2. Sharing the bedroom including the closet with the sibling	Same as above (Figure 4.32)

(Figure 4.31) Transforming one part of the living room into a play area



(Figure 4.32) Lack of space forced the children to share a bedroom

Rupa does not like living in an apartment. She needs more space: "*I miss one extra room … if I would have one extra room, I would have set up everything for him … maybe I'd have decorated fully with my son's need. Like computer, TV, only his DVDs, only his cars.*"

Now, Rupa hopes to change the small table in the living room and add a study table for her son. She would like to change the wall paint to bright colors because her son does not like

dark ones and replace the carpet with tile because it is easier to clean. However, if she had the opportunity, she would choose to live in a house without hesitation:

> *Backyard for space … I don't need to go every time for park … if its backyard and fence, just go out, play with your sister … I would call at least two of his friends … that's the thing I'm missing every, every time. I wish I had free space for them, which I do not have here.… When my husband was alive, we planned to get a house, sell this one. Suddenly he's gone, so we had to drop everything … house is always better.*

Rupa, found herself suddenly alone after her husband's death. Losing her 'source of support' has truly affected her ability to face the challenges of raising Shushman and his sister. Although she has done the least physical modifications compared to the other two cases, she seemed to be the most one in need of one. Its not because she doesn't want to, but because of the limited flexibility of modifying a rent apartment in addition to the limited fund she has.

4.4 Chapter Summary

This chapter has provided answers to the research questions from the points of professionals working on creating autism-friendly home environment (architects and occupational therapists), as well as families living with children with autism. Furthermore, autism-related challenges and physical modifications to the home environment have been explored via the three case studies representing three housing typologies. The next chapter will discuss these findings in relation to literature and the concept of therapeutic landscapes theory.

CHAPTER 5

DISCUSSION

I will begin this chapter by discussing the top findings of each of the three phases of this research while relating them to the literature. I will then discuss the role of modifications for shaping the home environment as a therapeutic landscape. Finally, I will outline the role of organizations, programs, and funding in creating an autism-friendly home environment.

5.1 Similarities and Differences

Analysis of the testimonies of the architects, occupational therapists, and families with children with autism reveal many correlations to the literature about the most common challenges and the modifications adopted in the home environment due to having a child with autism. I will outline the similarities and the differences in the findings among the three phases of this research, while comparing them and connecting them to the literature.

The three research phases provided an opportunity to analyze and compare the different perspectives of professionals involved with children with autism in their home environments (architects and occupational therapists) and the families and caregivers of children with autism. Both architects and occupational therapists were asked about the challenges that should be addressed to create an autism-friendly home environment. The same

inquiry was discussed with families with children with autism through the online questionnaire and face-to-face narrative interviews. It was interesting to learn that the professionals did not emphasize the challenges faced by family members (parents and siblings) as they focused on the needs of the child with autism. For example, the design strategies suggested by architects were directed at the creation of an environment that would respond to the social and communication, sensory, safety, and behavioral impairments of children with autism. The families surveyed in phase two and those interviewed in phase three, however, emphasized the significant everyday psychological, social, and physical struggles faced by the family members because of having a child with autism at home. Reported psychological challenges associated with parenting a child with autism included: a high level of stress; anxiety; depression; embarrassment; decreasing of self-esteem, and; worry about the future. Parents also reported social challenges, including: the feeling of isolation from friends and community; bad relationships with neighbors, and; decreased marital happiness. Exhaustion due to increasing workload, round-the-day supervision of their children with autism who lack a sense of danger, and the exposure to injuries or abusive behaviors contributed to the parents' struggles in the home environment. These reported daily challenges are consistent with the findings of many researchers (Myers et al. 2009, Bromey et al. 2004; Trute and Murphy 2002). Gardiner and Laracci (2012) argued that families of children with autism experience greater levels of psychological challenges and a lower quality of life than families of children with other developmental disabilities, such as Down Syndrome. The chronic parenting stress contributes not only to the parent's vulnerability to physical and mental health problems but also to exacerbating the challenging behaviors of their children with autism (Barker, Mailik, and Smith

2014). It was believed that children with autism are very introverted and that they do not understand the feelings of people around them; however, this perception has been challenged recently. Wertz (2012), an experienced occupational therapist who observed hundreds of parents and children with autism, suggested that children with proximity to adults who described themselves as stressed or uncomfortable tend to exhibit more-frequent negative autism-related behaviors, including repetitive movement, decreased response time, reduced social interaction, communication problems, and reduced gross motor ability. She also noticed that many children respond in remarkable ways to changes in the attitude of their parents or caregivers, by quickly reversing the negative behavior. Thus, Wertz stressed the importance of prioritizing the physical, mental, and emotional well-being of mothers and caregivers, and emphasized that the entire family system will be positively affected if only one person in the family system becomes more comfortable. She concluded that the home environment should not only be friendly for the child but also for the other family members.

Interestingly, the family survey in phase two and the lived experience investigated in phase three confirmed the findings of a recent study (Bromley et al. 2004) regarding the correlation between the level of psychological distress and the level of support from within the family. Single mothers showed higher levels of depression, distress, and lower adjustment than those mothers living with their spouse. A painful statement was noted by a mother in phase two:

> *Having two children with special needs equals massive chronic stress for a single mom.*

Similarly, a single mother (separated) interviewed in phase three reflected a higher level of depression in her tone of conversation when compared to the married mothers.

In addition, the challenges experienced by siblings were not emphasized by the professionals interviewed in phase one, although clearly challenges faced by siblings were demonstrated by the families in both phase two and three. Siblings were also the reason behind home modifications in 15% of the families surveyed in phase two. Siblings tended to feel neglected, less loved, and abandoned, as their parents are busy caring for the individual with autism. The siblings were also unable to maintain healthy social relationships with their peers, given the problems with inviting them to their homes. Moreover, the siblings face the risk of injury, lack of privacy, and sleep disturbance, especially when sharing a bedroom with a sibling with autism. As described by one of the mothers interviewed in phase three: "*I wouldn't say he has a regular life, like a regular brother.*" These findings were consistent with the literature (Baker-Dunbar 1998; Pengelly et al. 2009; Myers et al. 2009; Smith and Elder 2010).

5.2 The Impact of Housing Typology

The effects of the three housing typologies (apartment, attached house, and detached house) on increasing or alleviating the challenges associated with having a child with autism at home have been investigated from the perspectives of both professional (architects and occupational therapists) and families. There was a consensus among professionals that houses (either attached or detached) are better than apartments in accommodating the needs of

individuals with autism and their families. The comments of surveyed families in phase two and the lived experience of the families interviewed in phase three confirmed that living in a detached house is the most preferable option, whereas living in an apartment is the least. This finding is consistent with the literature correlating housing type to the mental and emotional well-being of the inhabitants. Fanning (1967), Bagley (1974), Richman (1977), and Evan et al. (2003) suggested that residents of single-family detached homes typically have better mental health than those living in multiple dwelling units. Four main housing characteristics were identified in order of priority as the benefits of detached single-family housing typology: (a) unit size, (b) outdoor space, (c) flexibility for adaptation, and (d) proximity to neighbors.

(a) Unit size

According to the results of the online questionnaire, the average number of rooms for an apartment was two rooms; for an attached house (townhouse) four rooms; and, for a detached house, it was more than four rooms. Moving to a larger-size unit was desired by most families living in either an apartment or an attached house. A mother interviewed in phase three living in a relatively large house was even willing to move to a larger house. A small unit exacerbates the challenges faced by all family members because of lack of privacy: *"... the apartment is so small there's no privacy or solitude for anyone," "... the apartment is very small and it is difficult for anyone to have anytime to themselves.*" Lack of space for family activities was also evident in smaller units. Families may have to sacrifice the common areas in order to meet the needs of their children with autism; as noted by a mother living in an attached house, "*...we needed to give our ASD son his own space, which meant giving up common living areas,*

further restricting our space." The overcrowding of a small space also contributes to increasing sensory stimulus, such as noise and clutter, and therefore to increasing autism-related behaviors: "...*the space is cramped and he is very noisy. We are in attached housing. This is stressful on all involved*." A parent of a girl with severe autism appreciates the relief their house provides to the family: "... *we are fortunate to have a bedroom for her and a big house to find sanctuary from her manic episodes*." These reasons place a high priority on unit size among autism-friendly housing characteristics. The importance of a spacious home environment that can accommodate therapeutic home modifications for both patients and caregivers has been acknowledged in earlier literature (Dononvan and Williams 2007).

(b) Outdoor space

The importance of outdoor space in shaping a healing environment for children with special needs, including autism, is well established in the literature. Harting et al. (1991) and Gulwadi (2006) suggested that time spent in nature provide benefits such as reducing stress and restoring attention. Taylor et al. (2001) suggested that children with attention deficit disorder perform better on cognitive tasks after walking in nature than after walking in an urban area. The healing effects of nature and outdoor spaces have inspired landscape architects to design therapeutic gardens where children with autism can play, learn, and be trained to overcome common challenges in a safe and fun environment (Sachs and Vincenta 2011; Hebert 2003). In phase one, the interviewed architects and OTs emphasized that a secured outdoor courtyard can benefit children with both hyper- and hypo-sensitivities and

enrich the therapy environment. In phase three, the two interviewed families who live in either an attached and detached house prepared their backyards as a safe place for their children to play with minimal supervision.

(c) Flexibility for adaptation

Living in a multiple-family dwelling restricts family control over their unit and their ability to adapt it to their needs. It was evident from phase two and three that the magnitude of the implemented modifications in apartments was the least among the housing typologies, despite the long "wish list" of modifications found in many cases. Although other factors could be involved (e.g., financial limitations, rental restrictions, etc.), this finding confirmed the OTs' and architects' concerns in phase one that housing typology, among other variables, restricts family plans for modifications. The flexibility associated with detached housing enabled some surveyed families to draw long term plans for accommodating their children with autism within their properties when they grow up.

(d) Proximity to neighbors

Findings of phase two and three confirmed the concerns of OTs in Phase one, regarding the negative impacts of having a neighbor on the other side on the wall. The children with autism living in apartments and attached houses were disturbed by noise from neighbors: *"...the closeness of my neighbors causes noise that sometimes affects my daughter as she has high anxiety and worries about strangers."* Conversely, some neighbors who were unaware of autism characteristics frequently complained about the noise or inappropriate behaviors of the

child within the common areas of the building (i.e. yard, shared entrance, corridors, etc.), which, in turn, contributed to poor relationships with neighbors.

5.3 Home Modifications as Therapeutic Landscapes

Therapeutic landscape is a conceptual framework for analyzing how the physical, social, and symbolic environments contribute to physical and mental health and wellbeing (Gesler, 1992; 2003). Its early development was derived from three main lines of thought, where: (1) cultural ecology and environmental psychology underlined the healing effect of nature and the significance of building design; (2) structuralism contributed ideas on social interactions and power relations in health settings, legitimization and marginalization, and health consumerism; and (3) social science brought in ideas on the importance of beliefs, feelings in places, and the symbolic power of myths and stories (Curtis et al 2007). As pointed out by Gesler and Curtis (2007), these lines of thoughts have been operationalized and respectively referred to as physical, social, and symbolic environments.

Since Gesler introduced the concept in 1991, the notion of “therapeutic landscape” has been actively employed to better understand the dynamics between places and wellness (Williams, 1999). Recently, these investigations have extended from exploring the attributes that may make a natural place such as a beach (Collins and Kearns 2007), a spa (Gesler, 2003) or a national park (Palka,1999) therapeutic, to considering the linkages between health and everyday spaces within communities and cities, such as community gardens (Milligan, Gatrell,

& Bingley, 2004).) and zoos (Hallman 2007). They have also expanded to consider the wellbeing of special populations and marginalized groups, such as alcoholics (DeVerteuil et al 2007), support group users (Davidson and Parr 2007), the homeless (Bridgman 1999), and people with mental disabilities (Geores and Gesler 1999). Further, the therapeutic landscapes theory has been extensively employed to explore the therapeutic properties of healthcare sites and services, including hospitals (Gesler and Curtis 2007, Crooks and Evans 2007), assisted living residences (Cutchin 2007) and the home (Donovan and Williams 2007).

The therapeutic landscapes concept present an ideal framework from which to explore the role of physical home modifications in transforming the home environment into a space of healing. The following discussion draws upon the wealth of information shared by the survey respondents and the interviewed families about the impact of implemented home modifications on the quality of life of their children with autism and other family members. When considered along with the collective experiences of the families, it was possible to identify certain themes that were aligned with the three therapeutic environments discussed by Gesler (2003): physical, social, and symbolic. These themes indicated that the implemented modifications positively affected the families' experiences of home and contributed to their physical, psychological, and social wellbeing. Table 5.1 lists these themes along with the family members positively and directly affected by them. Each subtheme is illustrated with the help of relevant quotes from the respondents. These themes are discussed below in connection with the challenges identified in Chapter 4 and in relation to the literature.

Before discussing the therapeutic themes, it is important to highlight that the therapeutic value of a particular environment is increasingly acknowledged by researchers as context dependent (Donovan and Williams 2007, Martin et al 2005); that is, the physical, social, and symbolic aspects of therapeutic home environments cannot be taken for granted. Dunkey (2009) suggested that being present in a particular healing landscape does not necessarily produce a therapeutic effect but it's an individual's set of characteristics and interaction with a socio-environmental setting that produces a therapeutic outcome. Therefore, the therapeutic value of the elements listed in Table 5.1 may differ for each family based on factors such as the severity of autism, the presence of particular autism-related challenges, or specific housing or family characteristics. However, Table 5.1 presents the factors defined as therapeutic by most of the families surveyed. Researchers have also acknowledged that interactions between the distinct environments play an important role in defining the user's experience (Muenchberger et al. 2012, Gesler and Curtis 2007). For example, a safe physical environment for the child was reported by many parents as contributing to their experience of home as a symbol of relaxation, comfort, and reduced stress. Similarly, it was evident from the study that the psychological wellbeing of parents was determined by a combination of physical, social, and symbolic factors, as presented in Figure 5.1. This complex mesh of interactions and effects, together with the context-dependency of therapeutic factors, makes it difficult to establish a particular environment as superior for the wellbeing of the families. It should also be noted that Table 5.1 only lists the physical modifications that have shaped home environments into therapeutic landscapes. Other factors such as availability of quality home-treatment services,

respite service, family support, and funds (Hodgetts 2013, Bromley 2004), although important in forming an autism-friendly home environment, are outside the scope of this study.

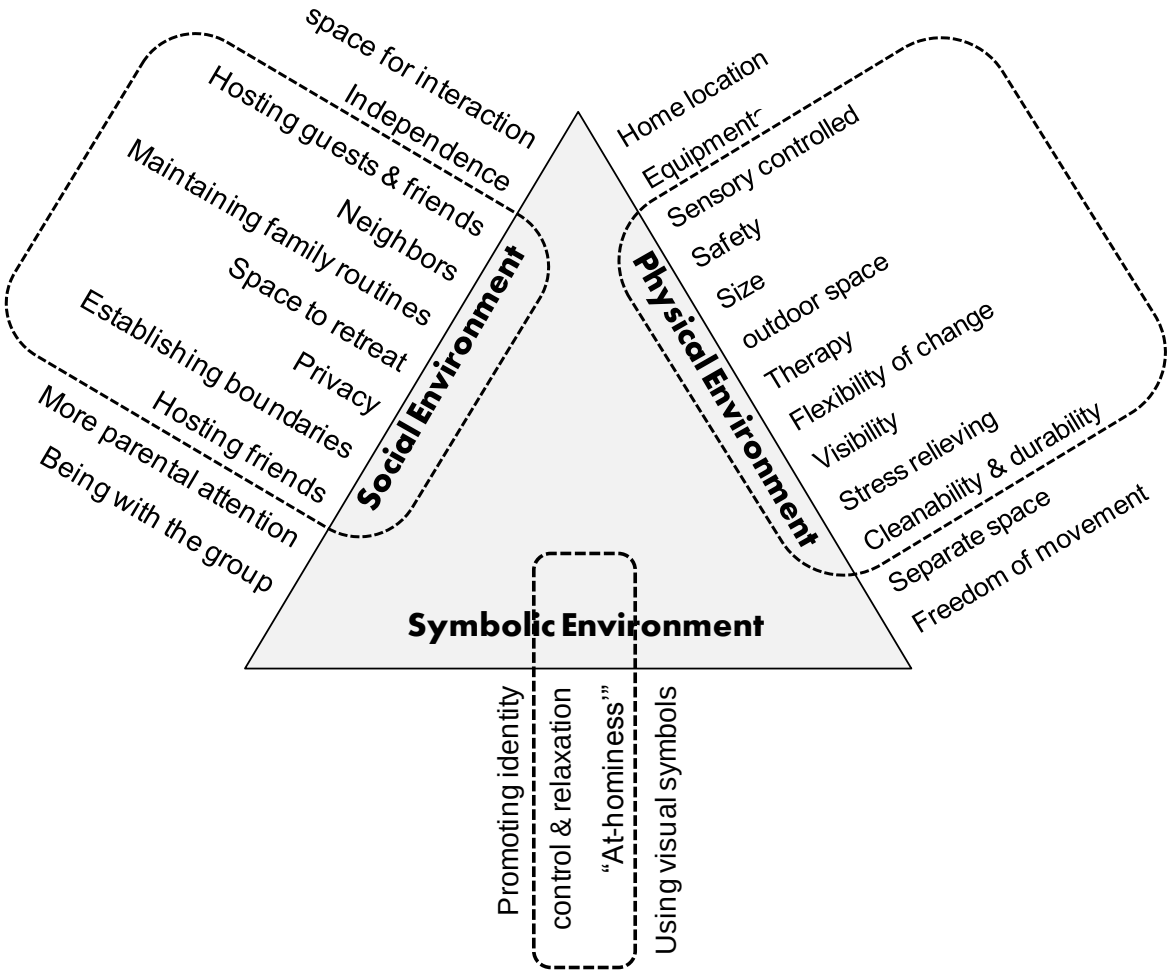


Figure 5.1 Environmental factors affecting the psychological wellbeing of the parents.

	People subtheme applied to	Themes	Examples of relevant quotes
(1)	**Physical Environment**		
	Whole family	Safety for all	▪ *It gives us peace of mind not worrying about the child wandering off … We can relax more knowing he is safe.* ▪ *He wanders if able to and these have stopped him from wandering into dangerous areas.* ▪ *We avoided injuries by keeping his sister … away from him.*
		More space for all	▪ *We added 1000 square feet on our home in order to give all of us more space … it made a world of difference.*
		Accessibility to safe outdoor space	▪ *We fenced the patio so we can enjoy outdoor lunch without him running around.*
		Home location	▪ *We are fortunate to live in a quiet neighborhood far from the main road*
	Child	Accommodating gross-motor equipments	▪ *The physical outlet (trampoline, etc.) helped to get aggression out.*
		Sensory controlled environment	▪ *We had to move from an apartment to house because he could not cope with extra noises from other families* ▪ *We had a much larger sensory room. ...sound proof the house...*
		Space for therapy & play	▪ *… set him up with a playroom in the basement so he can have an indoor playground during winter.*
		Freedom of movement	▪ *We are able to give our child more freedom to explore and move around/bicycle safely.*
		Flexibility to accommodate future needs	▪ *I wish to build her an apartment in the back so that when the time comes for adulthood transition she will have a place to learn independent living, while being safe in "our compound."*
	Parents	Space visibility to ease supervision	▪ *I feel better because now he can play near me, and I can see him while I'm cooking.*
		Stress relieving environment	▪ *Without these modifications, my level of stress would be elevated with the multitude of things that I have to worry about*
		Cleanability & durability	▪ *I don't have any carpet … it would probably be a nightmare … the ceramic floor is better … just clean and wash. It's better this way.*
	Siblings	Separate space	▪ *My other son shared the same room with my autistic son and could not sleep well at night because of him. Now they have separate rooms. It is a lot better now.*
(2)	**Social Environment**		
	Whole family	Hosing guests	▪ *Sometimes we feel isolated when we can't have people over for long period because of his behavior.*
		Neighbors	▪ *Neighbors have complained about loud screaming or pounding on the walls at high stress times....*
		Maintaining daily family routines	▪ *For years, we did not play our CDs or the radio because the noise would upset him.*
		Multi-use space to encourage interaction	▪ *...basically keep all his toys and computer in main living are as he refuses to play alone up his bedroom.*
	Child	Independence	▪ *We have made modifications … all make things easier for him to be more self-reliant.*

	Being with the group but not in focus	▪ *…have many different stations in the room with puzzles, toys, etc. that can keep her occupied while others are watching TV or others are reading, etc.*
	Space to retreat from overwhelming social activities (de-stress)	▪ *… a more sensory calming space that he can retreat to.*
Parents	Privacy (marital activities)	▪ *We added places he is unable to have access to (…, guest bedroom, Mum and Dads room to watch movies unsurprised) … for sure he is no longer in our space all the time.*
	Establishing boundaries for social activities	▪ *Gates are our way of letting him know he is not allowed in here. Although he can climb, he understand that is "no."* ▪ *He now knows that he has specific areas around the house, he can play.*
Siblings	Hosting friends	▪ *… added a designated space for other children to host friends, separate from our autistic child.*
	More parental attention	▪ *He requires more attention, and we often feel our younger son gets left out because he's not less loved.*
(3)	**Symbolic & Personal Space**	
Whole family	"At-hominess'"	▪ *We put up an expensive front-yard fence to allow us to go outside … when we couldn't go outside, we felt like prisoners in our own house.*
Child	Promoting identity (Personalization)	▪ *We made one wall in our living room that is her wall for artwork, stickers, or any sensory things she needs to do with it, and her siblings get to hang items too.*
	Symbolizing activities	▪ *Here in the living room … the therapist has their corner with a table … when there is that kind of set up, he knows when sites there, it is work time. I think it's important making that connection.*
Parents	Place of control , comfort and relaxation	▪ *It's a place, for sure, where you know you can be in control and can relax.*
		▪ *At least with the changes I've made in home, I feel more confident that she will be safe if I close my eyes to take a nap.*

Table (5.1) Therapeutic landscape themes of home modifications

(1) Physical environment

The physical environment, including the location of the home, outdoor and indoor designs, furniture, and the micro-environment of individual rooms, has a significant influence on the wellbeing of the child with autism and his or her family. Properties of the physical environment, such as safety, size, and the availability of outdoor space were reported as essential to the wellbeing of all family members. The lack of a sense of danger was rated as the top autism-related behavior triggering home modifications by the survey respondents. Installing safety measures such as fences, gates, and removing furniture with sharp edges contributed not only to the physical wellbeing of the child but also provided peace of mind to the parents, significantly reducing their psychological stress. Securing a spacious home space, either by relocating to a larger home or by adding space to the existing one, also contributed to the wellbeing of all the family members.

Home modifications were mainly directed at securing a therapeutic physical environment that met the child's sensory, gross-motor, and occupational needs, as reported by 82.8% of the respondents to the online questionnaire. Modifications to control the sensory environment helped reduce the negative behaviors and sensory overload that hindered the children's activities. The positive impact of home modifications on reducing autism-related behaviors also helped parents to manage the high levels of stress associated with parenting children with autism, which is consistent with the literature (Bromly et al. 2004; Hodgetts and Nicholas 2013). The modifications also ensured adequate space for various activities, such as therapy, playing, and sleeping. For example, a quiet corner in the living room or basement for therapy, with minimal distractions, was a commonly implemented modification that also

ensured that the bedrooms were used exclusively for sleeping. This improvement was endorsed by all the interviewed mothers and has also been recommended in recent literature (Engelhardt et al. 2013). Further, providing safe and contained places, both outdoors and indoors, where the children could move freely and exercise, not only improved the children's gross motor skills but also promoted self-reliance.

The flexibility to accommodate future family demands is another important therapeutic property that is needed in the physical environment. Parents reported that the ability to modify the physical environment of their homes helped them overcome their anxiety about the children's living arrangements once they grew up. Knowing that almost 79% of young adults with autism tend to live with their parents (Ahrentzen et al. 2009), the parents wanted to develop the family home as a safe space for their children to live with dignity and independence in their adulthood.

Visibility, cleanability, and durability are important therapeutic properties of the physical environment that significantly contributed to the parents' physical and psychological wellbeing. Parenting children with autism is extremely demanding, requiring full-time, requiring "100% attention," as noted by an interviewed mother. Home modifications allowed parents to continue caring for their children with autism, while managing other household activities. For example, ensuring wide visibility by eliminating the partition between the living room and the kitchen was a modification that allowed mothers to keep an eye on their children with autism while cooking. Parents reported that household tasks were easier to undertake if they used cleanable and durable products. Modifying the physical home environment also helped parents to establish boundaries and communicate orders indirectly to their children; for example,

installing locks and gates defined the zone where the child was allowed. Overall, the modifications gave parents some time to enjoy relaxing activities, which are highly recommended for their physical and mental wellbeing (Wertz 2012). Providing separate spaces for the siblings of the children with autism can also contribute to making the physical environment therapeutic. Most families who moved to larger houses or expanded existing ones reported that providing separate bedrooms for siblings contributed to enhancing their sleeping patterns and protecting them from the aggressive behaviors of children with autism.

(2) Social Environment

The social aspect of the home environment pertains to maintaining healthy relationships with family members, engaging in social interactions with neighbors and friends, and the ability to perform social activities and routine activities. These are also important to the family's wellbeing. Home modifications contributed to restoring the families' relationships with the community. The inability to host friends, relatives, and guests at home because of the fear of inducing autism-related behaviors was a common complaint among the surveyed families and was also cited in the literature (Hodgetts and Nicholas 2013). Some home-modification strategies, such as providing a calming space for the child to retreat to if annoyed by visitors, were reported as contributing to alleviating this problem. This restorative space was also discussed in the literature as highly valuable for the occupational, social, and emotional wellbeing for the family members (Pengelly 2009). Similarly, the social lives of siblings improved with the addition of a designated space to host friends, which ensured that the child with

autism was not disturbed. Installing good-quality sound insulation also helped reduce the emitted noise and thus restore relationships with the neighbors.

Having a child with autism at home, with a multitude of autism-related challenging behaviors, usually dominates and controls the daily life of the family, as indicated in the literature (Bromly et al. 2004). The disruption, noise, aggression, and the child's lack of a sense of danger, among other challenging behaviors, affect the ability of the entire family to maintain a daily routine or undertake habitual activities. For example, 62% of the survey respondents reported dedicating most of their time to supervising their children with autism, which, in turn, took a toll on other social activities. Physical modifications to home environment, such as installing safety measures, rearranging the interiors, or adding new space to the home, helped the families better manage their daily activates and routines.

Home modifications also helped in improving social interactions within the household. Creating a child corner in the living room, a commonly reported space arrangement, satisfied the child's need for being physically close to the family members without always being in focus. Engaging the child in more daily activities with the family, such as a lunch in the backyard, was possible after enhancing safety measures to prevent elopement. Parents reported that because they had to devote most of their time to their children with autism, the siblings tended to feel neglected and abandoned. By reducing the demands and challenging behaviors associated with autism, home modifications allowed parents more time for the other child in the house and helped alleviate their emotional pressure.

Home modifications also provided parents with the privacy they needed to relax and enjoy their marital relationship, which is often negatively affected by autism (Hodgetts 2013; Myers et al. 2009).

(3) Symbolic Environment

The last theme is the experience of home as a personal and symbolic space (defined as a space for self-expression, identity, and personal control) for the children with autism and all other family members. An important quality of the home environment is promoting a sense of "at-homeness," a phenomenological concept that refers to the ability of the residents to be what they most comfortably are and to do what they most wish to do in everyday life (Seamon 2012). Autism dramatically affects this sense by restricting what families can do or where they can go, transforming the house into a place of daily struggle. Feeling like prisoners in their own homes was a common expression used among many respondents to the online questionnaire, which is consistent with much of the literature (Hodgetts 2013; Myers et al. 2009; Brinchmann 1999). Home modifications contributed to restoring the sense of "at-homeness" among the family, by allowing them the freedom to undertake more activities without barriers and to experience fewer restrictions in their daily life. Physical interventions to reduce sensory stimulation and challenging behaviors contributed to creating a quiet, comfortable, and loving home environment, turning the home into a safe haven and a symbol of "*control and relaxation*" for the whole family, as noted by a surveyed mother.

Children with autism often struggle with their self-esteem because of increased insight, feeling "different," and lacking of self-confidence. Their talents are often overshadowed by

their negative behaviors and social impairments (Tanona 2011). This makes it difficult for them to form an independent identity and to work out who they are and what their values are when they grow up. Simple, yet effective, physical arrangements can turn the home environment into a landscape of identity and self-confidence for the child with autism. For example, many families prepared personal corners for their child with autism in the living room, where his/her artwork is displayed and praised, which supports the importance of celebrating the daily accomplishments of the child with autism and building his/her identity and self-esteem (Tanona 2011). Physical arrangements of the home environment were often a means of communication to overcome the cognitive barriers associated with autism. For example, a corner with a table and visuals on the wall symbolizes therapy time, the child has to sit and listen. Such silent language of visual symbols is often used in connection with autism.

Consistent with the literature (Pengelly et al. 2009), many parents of children with autism reported having difficulty when going out in their community, socializing, or attending social events because of society's lack of understanding of what autism is and what is involved in caring for a child with autism. The parents and the architects interviewed in phase one of this study believed that the community is neither designed nor prepared to support the demands of autism. Having this in mind, parents considered home as "the best place" that they can be in control in any situation, can get support, and can best deal with the demands of their children with autism. A large portion of the potential home modifications was for rendering the home as a place of control and coping.

5.4 Negative Experiences with Home Modifications

Despite the notable role of the implemented modifications in shaping the home as a therapeutic landscape for children with autism and their families, very few of the surveyed families pointed to a negative home experience as a result of home modifications. Sometimes the positive occupational gain for the child was associated with a negative one for the family. A respondent to the online survey noted: "*The gates and locks make it hard for the rest of us to move around our house comfortably.*" The same respondent expressed her disappointment, as other modifications did not help improve the behavior of the child as expected: "*We had the front porch fitted with a special rolling gate, hoping that they could go outside and still be watched, but they did not like to go out there, so that was an expensive waste.*"

Other families were disappointed that the modification they needed exceeded their financial capacity: "*If I could I would move to a home that had a fenced backyard and an extra room for my autistic daughter, but we make do with what we have.*" Finally, families were aware that home modifications are temporary solutions, because as children grow up, their needs change: "*A great deal of problem solving for ASD parents are temporary solutions; as their children grow and change, so do the challenges. It's difficult to keep on top of them at times.*"

5.5 Therapeutic Design Goal Matrix

As mentioned earlier in this chapter, one of the criticisms against the current practice of designing autism-friendly home environments is that it emphasizes the needs of the child with

autism while almost neglecting the physical, social, and psychological challenges encountered by the parents and siblings. Recent research (Wertz 2012) highlights the importance of designing home environments that consider the needs of not only the child with autism but also those of the other family members. From the preceding discussion on the role of modifications in shaping the home environment as a therapeutic landscape, I suggest that we as geographers can contribute to broadening the perspective of home designers by shedding light on areas (or users) that are under-emphasized in the current practice.

	Whole family	**Child with ASD**	**Parents**	**Siblings**
Physical Environment	- Safety (indoor & outdoor) - More space for all - Accessibility to the outdoors - Quiet neighborhood	- Sensory controlled environment - Space for gross-motor equipment - Freedom of movement - Space for therapy - Space for play - Flexibility to accommodate future needs	- Maximize space visibility to ease supervision - Use of cleanable and durable material to ease household management - Stress relieving environment	- Space separation
Social Environment	- Minimal negative impact to and from neighbors - More family activities - Zonable (multi-use) interior spaces	- Promote independence - Proximity to the group but not in focus - Space to retreat from overwhelming social situations	- Maximum visibility to ease supervision - Privacy for marital space - Clear boundaries for social activities - Future expandability	- Capacity to host friends - More parental attention
Symbolic Environment	- Promoting sense of at-homeness	- Promoting identity (personalization) - Using visual symbols for activities and spaces	- Promoting sense of relaxation and control	

Table 5.2 Therapeutic environments: Design goal matrix derived from families' living experiences.

Table 5.2 is a matrix that relates the needs of each family member to the three dimensions of the therapeutic environment. The cells represent the design goals pertaining to each family member in a certain environment. The goals are derived from the identified therapeutic themes discussed earlier in this chapter. The matrix serves as an exploratory framework that can assist home designers in developing design strategies to achieve the stated design goals for example, applying sound-proofing materials to achieve a sensory controlled environment. The matrix can also help architects and occupational therapists suggest modifications to a certain household such as, eliminating the partition between livingroom and kitchen to allow monitoring the child while cooking. They can use the matrix to determine the goals that have been satisfied and those that need to be further enhanced. The matrix can be used as a tool to inform policy makers in developing building codes and design guidelines for autism.

5.6 Chapter Summary

In this chapter, the findings described in Chapter 4 have been further analyzed using the framework of the therapeutic landscape theory. It can be concluded that implementing physical modifications can help in shaping the home environment as a therapeutic landscape of healing and, in so doing, enhance the quality of life of children with autism and their families. Housing characteristics such as large unit size, less proximity to neighbors, flexibility for adaptation, and the availability of outdoor space make the home environment more conducive to the occupants' autism-related requirements. Lastly, this chapter suggests that geographers can play an important role in informing the design of autism-friendly homes and policies.

CHAPTER 6

CONCLUSION

While the objective of this thesis was specific, the research results have broad implications. The purpose of this investigation was to understand the challenges faced by children with autism and their families in the home environment and how physical elements of the home environment can be designed or modified to alleviate these challenges and create an autism-friendly home. Data for this research was gathered in three phases: (1) through semi-structured interviews with professionals experienced in creating and/or modifying the home environment to make it autism-friendly [interviews with architects (n = 4) and occupational therapists (n = 2)], in addition to a focus group of OTs (n = 8); (2) through an online questionnaire survey involving families having children with autism living in various housing typologies (detached house, attached, and apartments) across Canada and the USA (n = 168), and; (3) through diary-interviews with three families (each representing one housing typology) who have children with autism. These interviews explored their lived experience and how their quality of life was affected by the modifications made. The findings of the investigation were presented in Chapter 4. They were synthesized and discussed in Chapter 5 so as to highlight the role of physical modifications in shaping the home environment to become a therapeutic landscape for healing. The findings also shed light on which housing typology is closer to being autism-friendly.

This chapter will summarize the significant results from both Chapters 4 and 5, as well as discuss study limitations. It will also explore the wider relevance of the research, together with the contributions to the geographical and architectural literature. Finally, future research directions will be presented.

6.1 Overview of Significant Findings

The most commonly cited challenges and related design strategies considered by architects (n = 4) while designing homes for families with autism could be organized into four categories: social and communication, sensory, imagination, and behavioral (Table 4.1). OTs (n = 10) also defined and ranked a list of autism-related behaviors associated with a deficient home environment. Distractibility was identified as the top autism-related behavior, followed by restlessness. OTs recommended four types of modifications related to mobility, safety, space organization, and sensory challenges (Table 4.2).

It is impractical to recommend a single set of design interventions for all homes having children with the same degree of autism. Not only is each child a unique individual with distinct requirements, but there are also many differences between families, homes, and cultures that would make this task impossible.

Interestingly, the interviewed architects and OTs did not mention the challenges faced by family members (parents and siblings) living with a child with autism as a reason for modifying the home environment. They mostly focused on the needs of the child with autism.

This important finding suggests that research on creating autism-friendly home environments should be multi-disciplinary, and include a holistic understanding of the needs of all the family members.

Interviews with architects also revealed that the current design trends, for both residential and public buildings, do not consider the needs of individuals with autism. This was confirmed by the families with children with autism in the later phases of this research. The architects interviewed suggested that the absence of design for disability from the architectural academic curriculum was responsible for the dearth disability-friendly designs in general and for autism in particular.

According to the result of the online questionnaire, 87% of the respondents noted that sensitivity to noise was the most common sensory problem among children with autism, followed by visual sensitivity (67%), sensitivity to lighting (66%), temperature (54%), and colors (20%).

The lack of a sense of danger was the most common behavior that triggered home modifications, as reported by 53% of the respondents, followed by tantrums (28%) and aggression (24%).

Having a child with autism at home had a significant negative impact on the family members (parents and siblings). Psychological and emotional challenges (e.g., stress, embarrassment, and depression) were experienced by 76.2% of the parent participants, followed by social challenges (e.g., isolation from friends and community, marital unhappiness, poor relationship with neighbors, and loss of career). Physical challenges (e.g., destruction of

household items, injuries to siblings and parents, and exhaustion) were reported by 42.6% of the parents. Siblings felt abandoned and less loved as their parents prioritized their child with autism.

Various modifications to the home environment were implemented by the families included in the study. The majority (81%) were primarily to deal with challenges related to the child with autism, while 15.55% targeted the siblings. Three main categories of modifications were identified: (1) creation of extra space either by moving to a larger home (27%) or by adding space to the existing home (40%); (2) modifications to the existing space(35%), such as addition of safety measures (e.g., gates, fence) and space re-organization (e.g., adding storage to reduce clutter) (24%),and; (3) use of technological tools (67%) to enhance safety (e.g., locks and alarm systems).

The diary interviews with the families and the responses of the survey participants were analyzed using the therapeutic landscapes theory to identify the linkages between home modifications and wellbeing for all family members. From the collective experiences of the families, it was possible to extract themes that aligned with the three therapeutic environments of Gesler (2003): physical, social, and symbolic. The themes indicated that the implemented modifications positively affected the families' experiences of home and contributed to their physical, psychological, and social wellbeing.

Themes pertaining to the physical environment such as safety, unit size, and access to outdoor space were recognized as being therapeutic to all family members (see Table 5.1, p.136). While factors such as controlling the sensory environment, accommodation of gross

motor equipment, ease of mobility, and flexibility to accommodate future needs were defined as therapeutic for the child with autism and significantly contributed to decreasing challenging behaviors, they also reduced the parents' psychological stress. Cleanability, moveability, and visibility are among the physical factors that also immensely contribute to the physical and psychological wellbeing of the parents.

The therapeutic social environment is shaped by the relationships between family members, social interactions with the community, and the ability to perform daily activities. It was evident that the home modifications contributed to lessening social isolation by enabling the family to host guests and friends, restoring their relationships with neighbors, and facilitating their daily routines. The modifications also contributed to the social wellbeing of the child with autism by fulfilling his or her need of being close to a group but not in focus. The provision of a sensory calming space to retreat to from stressful social situations is also helpful to a child with autism. Ensuring more private space for the parents can also help restore their marital lives, which usually deteriorate as a result of coping with autism.

Four themes related to the symbolic environment were identified: promoting a sense of “at-homeness” for all family members, promoting the child's identity, symbolizing activities, and promoting the home as a place of comfort, control, and relaxation for parents.

To help designers in recognizing the complexity of creating an autism-friendly home environment and the importance of addressing the needs of all family members, the identified therapeutic themes were organized to form a therapeutic goal matrix (Table 5.2, p.145). The

matrix can serve as the framework for developing further design strategies and policy guidelines for building autism-friendly homes.

The influence of the three housing typologies (detached house, attached house, apartment) on the challenges associated with having a child with autism at home have been investigated from the perspectives of both professionals (architects and OTs) and families. Responses confirmed that houses (either attached or detached) provide better opportunities than apartments with respect to accommodating the needs of the individuals with autism and their families. The comments of surveyed families in phase two and the lived experience of families interviewed in phase three confirmed that living in a detached house is the most preferable option while living an apartment is the least desirable. Four main factors favored the detached single-family housing typology: (1) larger unit size; (2) less proximity to neighbors; (3) more flexibility for adaptation; and (4) more outdoor space.

6.2 Study Limitations

One of the limitations of the study is that the semi-structured interviews were restricted to a few architects (n = 4). Of these, only one was from Canada due to the small number of architects living in Canada and worldwide with experience in designing for people with autism. This limitation was addressed through an extensive review of the architectural literature that, together with these interviews, served to highlight the most influential architectural elements that affect the behavior of the child with autism in his/her home environment.

The purposive and convenient sampling method used for selecting case studies for the in-depth diary-interviews did not cover the broad spectrum of autism or demonstrate the variety of challenges or home modifications. However, the purpose of these interviews was to shed light on the interviewees' lived experience in the different housing typologies (detached house, attached house, apartment), as well as to link the home modifications to the quality of life of the families. An investigation of the lived experience of families with other forms of autism (Asperger's Syndrome and ADD-NOS) and other degrees of severity (high functioning) is needed. The case studies also focused only on families living in urban areas (Great Toronto Area), although the on-line questionnaire used in phase 2 helped in addressing this limitation by involving families from a wider geographic area. Even so, an in-depth exploration of the experiences of families living in rural areas in needed.

Another limitation of this study is the lack of direct observation (mainly due to privacy concerns) of how children with autism and their families interact with the home environment. The diary-based interview method was used to overcome this limitation, where mothers were trained to record important observations. However, it was noted that the observations recorded by the mothers did not add much to what was addressed in their initial interviews. Furthermore, the interviews were conducted mainly with the mothers. Earlier literature suggests that the perspectives of fathers (Trute and Murohy 2002), siblings (Smith and Elder 2010), and if possible, the individuals with autism themselves (Baumers and Heylighen 2010) can broaden our understanding of the challenges and lived experience associated with autism. Opportunities for addressing these additional various perspectives are discussed in one of the following sections of this chapter.

Finally, although the effect of the gender of the child with autism and the socio-economic class of the family (Bromley et al 2004) on the challenges experienced in the home environment was implicitly considered in the online questionnaire, these factors need to be explicitly addressed in greater depth.

6.3 Policy Implications

The views of the participants and the lived experiences of the families with children with autism provided deep insights into the challenges associated with creating autism-friendly home environments and, thus, improving quality of life. Some preliminary policy implications can be drawn from this study. First, some families pointed to the lack of monetary resources as a barrier for implementing the required modifications. Funding programs such as Ontario Renovate offer forgivable loans to low-income elders and people with disabilities to help them repair and renovate their homes. However, these loans are mainly given to increase the physical accessibility of homes. Policymakers should consider extending the coverage to other autism-related modifications explained in the study, such as insulating the walls for those that have sound sensory sensitivity.

Autism has been excluded from building codes and guidelines, including those developed specifically for special needs individuals (Mostafa 2008). Given the growing prevalence of autism, building codes should be further updated to consider the needs of people with autism and their families. This study helps in identifying the most commonly reported autism-related challenges and the relevant home-based modifications. For example, buildings

should offer the flexibility to remove or modify internal partitions, (e.g., the partition between the living room and the kitchen) to allow for extended monitoring or a larger living space. To mitigate the major problem of noise sensitivity, building codes should enforce quality sound insulation between neighboring units, regardless of the housing class or typology.

Families living in Ontario Housing mentioned the restrictions on making any permanent modifications to their units. Policymakers should consider alternative housing for these families.

6.4 Contribution to the Field of Health Geography

Literature in human geography has emphasized the need to understand the experiences of individuals with autism as well as their families in the home environment (Pengelly 2009). This research contributes to the available evidence regarding the relationship between the physical elements of the home environment and the quality of life of children with autism and their families. It also sheds light on the potential modifications for these home elements.

Despite the increasing interest in studying housing modifications, there has been little interest in exploring how home modifications affect the experience and meaning of home among patients and their families (Williams 2002). This is particularly true in the case of mental or developmental disabilities (including autism) where research remains remarkably underdeveloped (Evans et al 2003, Pengelly et al 2009). This work contributes to the research

evidence that links home modifications to the well-being of families and their children with autism.

While the concept of therapeutic landscapes has been the focus of considerable interest in recent years, to the best of my knowledge, this research is a unique attempt at applying the therapeutic landscapes concept to analyze the home environment in the context of autism. Furthering our understanding of how families modify and experience their homes will help both professionals (e.g., architects and occupational therapists), as well as families, in ensuring that the home environment is therapeutic for all family members sharing the household with the child with autism. In addition, as pointed out by Williams (2002), this line of research contributes to the development of the concept of therapeutic landscape theory, as well to the ongoing debates in the human and social sciences on the meanings of space, place, and locale.

Although the concept of therapeutic landscapes has been increasingly applied in literature to examine the impact of long term home-care on the caregiver's experience and meaning of home (Williams 2002, William 2004, Donavan and Williams 2007), little is known about the caregiving for autism as a lifelong disability. The study provides insights into the multidimensional—physical, social, psychological, and emotional—challenges associated with caring for a child with autism and how the home environment can contribute to the caregivers' wellbeing.

The study also contributes to the limited body of literature on the application of therapeutic landscape theory to evidence-based design of the built environment. The existing literature has focused on the impact of the design of hospitals and purpose-built accommodation for people with disabilities on the health and wellbeing of the patients and

staff (Geslar 2003, Gesler 2004, Gesler and Curtis 2007, Muenchberger et al 2012). This study extends the application of the therapeutic landscapes theory to the design of the family home. The study proposes a therapeutic goal matrix that links the experiences of each family member to the physical, social, and symbolic environments of the therapeutic landscapes. The matrix can be further developed into detailed design guidelines. Thus, the study potentially contributes to a holistic approach for designing autism-friendly homes that goes beyond the discussion of specific features of the physical environment.

6.5 Contributions to the Field of Architecture

This research contributes to the field of architecture in many ways. At the outset, it contributes to the existing research on the relationship between architectural space and people with autism, which is an under-researched subject, despite the extensive research carried out recently on autism (Mostafa 2008). The limited available literature mainly focuses on educational spaces and the classroom environment (Vogel 2008, Scott 2009, Khare & Mullick 2009) or new residential spaces for adults with autism (Beaver 2010, Brand 2010). This work contributes to a notable gap in evidence-based research by addressing physical modifications introduced by individuals to create autism-friendly environments for children with autism and their families.

Second, as discussed in Chapter 6, when discussing the home environment in the context of autism, architects mainly focus on dealing with the child's impairments, sidelining the significant challenges encountered by the family members. This research alerts architects to

the potential impact of architectural intervention in improving the quality of life of the family members as well as the child with autism.

Third, the study highlights the importance of updating the architectural curriculum to include courses on architecture for disability. As argued by the interviewed architects, the absence of such courses is responsible for the lack of interest and knowledge among practicing architects in developing designs for people with disability in general, and with autism in particular.

Finally, by focusing on creating an autism-friendly environment, this study contributes to enhancing the built environment for not only for the people with autism and their families, but also for the general public. As argued by Simone Humphreys, one of the interviewed architects and a renowned scholar:

"If you design a beautiful autism environment it will uplift all people"

6.6 Future Research Directions

The limitations of this research, described earlier in this chapter, have brought forth new questions and several interesting avenues for future research. It will be interesting to learn how factors such as: the location of a household (rural vs. urban); the gender of the child with autism; the child's diagnosis on the spectrum (Asperger's Syndrome, ADD-NOS), and; the socio-economic class of the family affect the autism-related challenges in the home environment, or impact the design strategies to alleviate these challenges. Exploring the scene from the

perspective of the fathers, the siblings or, if possible, the children with autism themselves, can help broaden our understanding of how to create an autism-friendly home environment and enhance the quality of life of the whole family.

As most of the current research and practice related to designing autism-friendly homes focuses on the child's needs with little consideration of the other family members, researchers in the field of environmental psychology have been called upon to address the psychological and emotional needs of parents who are usually under a high level of stress as a result of parenting a child with autism.

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Appendix A

McMaster University
Inspiring Innovation and Discovery

McMaster University Research Ethics Board (MREB)

c/o Research Office for Administrative Development and Support, MREB Secretariat, GH-305, e-mail: ethicsoffice@mcmaster.ca

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Application Status: New ☐ **Addendum** ☑ **Project Number:** 2013 118

TITLE OF RESEARCH PROJECT:

Toward a Therapeutic and Autism-friendly Home Environment

Faculty Investigator(s)/ Supervisor(s)	Dept./Address	Phone	E-Mail
A. Williams	Geography	24334	awill@mcmaster.ca
Student Investigator(s)	**Dept./Address**	**Phone**	**E-Mail**
W. Nagib	Geography		nagibwf@mcmaster.ca

The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:

- ☐ The application protocol is cleared as presented without questions or requests for modification.
- ☑ The application protocol is cleared as revised without questions or requests for modification.
- ☐ The application protocol is cleared subject to clarification and/or modification as appended or identified below:

COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.

Amendment#2, cleared May 2, 2014

Reporting Frequency:	Annual: Oct-01-2014	Other:

Date: Oct-01-2013 **Acting Chair, Dr. D. Pawluch**

Appendix A-1

Email Recruitment Script for Architects/Occupational Therapists

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Masters Candidate)
Supervised by: Dr. Allison Williams

School of Geography and Earth Sciences

E-mail Subject line: McMaster Study – Toward an Autism-friendly Home Environment

.As part of graduate program in Geography at McMaster University, I am carrying out a study to explore the physical elements that affect the quality of life of autistic children and their families in home environment and how can these elements be designed (or modified) to create an autism-friendly home environment.

I am inviting you to answer a brief list of questions through an informal interview that take about 20-30 minutes of your time.

I have attached a copy of a letter of information about the study that gives you full details. This study has been reviewed and cleared by McMaster Research Ethics Board. If you any have concerns or questions about your rights as a participant or about the way the study is being conducted you can contact:

The McMaster Research Ethics Board Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administration, Development and Support (ROADS)

E-mail: ethicsoffice@mcmaster.ca

We would like to thank you in advance for your time and consideration. After a week, we will send you a one-time follow-up reminder.

Wasan Nagib

Masters Candidate

School of Geography and Earth Sciences

McMaster University, Hamilton Ontario

Tel: 905-525-9140 Ext: 28617

Nagibwf@mcmaster.ca

Appendix A-1-a

Email Recruitment Script for Occupational Therapists Focus Group

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Masters Candidate)
Supervised by: Dr. Allison Williams

School of Geography and Earth Sciences

E-mail Subject line: McMaster Study – Toward an Autism-friendly Home Environment

Dear (I will put her name here to personalize the letter),

As part of graduate program in Geography at McMaster University, I am carrying out a study to explore the physical elements that affect the quality of life of autistic children and their families in home environment and how can these elements be designed (or modified) to create an autism-friendly home environment.

I learnt from my supervisor (Dr. Allison Williams) that you are a member of a group of occupational therapists who meets regularly for discussing different professional related issues. I will appreciate should you communicate with the group members about their interest to participate and circulate the attached letter of information which gives them full details about the study. Then kindly let me know about the possibility of forming a focus group of 3-10 interested members and the time/place that is convenient for the group. You may use the attached message in approaching them empathizing that participation is voluntarily. Although your kind sport means a lot to my research, you should in no way feel pressured to do this. If you prefer not to take part I will appreciate your decision and will consider alternative data gathering methods.

If you, or any of the group members, need more clarification please contact me on the phone number and/or email address bellow. Please note that this study has been reviewed and cleared by McMaster Research Ethics Board. If you, or any or your group members, have concerns or questions about your rights as a participant or about the way the study is being conducted you can contact:

The McMaster Research Ethics Board Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administration, Development and Support

E-mail: ethicsoffice@mcmaster.ca

I would like to thank you in advance for your time and consideration.

Wasan Nagib, Masters Candidate, School of Geography and Earth Sciences, McMaster University, Hamilton Ontario, **Tel: 905-525-9140 Ext: 28617, Nagibwf@mcmaster.ca**

Appendix A-1-b

Email Recruitment Script for Occupational Therapists Focus Group (On behalf of researcher)

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Masters Candidate)
Supervised by: Dr. Allison Williams

School of Geography and Earth Sciences

E-mail Subject line: McMaster Study – Toward an Autism-friendly Home Environment

Dear Group members

Wasan Nagib, a master's student at McMaster University, has asked me to inform you about a study she is doing on creating Autism-friendly home environment. The study explores the physical elements that affect the quality of life of autistic children and their families in home environment and how can these elements be designed (or modified) to create a therapeutic home environment.

Wasan is seeking to conduct a 60-75 minutes focus group interview with occupation therapists whom are experienced in working with autistic children in home environment. She is looking forward to forming a focus group of 3-10 interested members at the time/place that is convenience to the group. Attached is a letter of information about the study. Please read it at your convenient time and get in touch with me if you are interested to participate and your preferred timing. If any of you would prefer to do individual interview, please contact Wasan directly.

I will follow up with you after one week. However, I would like to emphasize that participating in this study is totally voluntarily and none of you should feel pressured to participate.

Appendix A-2:

Email Recruitment Script Sent on Behalf of the Researcher

by Ontario Association of Architects (OAA)

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Masters Candidate)
Supervised by: Dr. Allison Williams

School of Geography and Earth Sciences

Sample E-mail Subject line: McMaster study about Autism-friendly Home Environment

Dear Architects,

Wasan Nagib, a McMaster student, has contacted OAA asking us to tell our members about a study she is doing on Autism-friendly Home Environments. The study explores the physical elements that affect the quality of life of autistic children and their families in home environment and how can these elements be designed (or modified) to create an autism-friendly home environment.

This research is part of her Master program in Geography at McMaster University.

The following is a brief description of her study. She has asked us to attach a copy of her information letter to this email. That letter gives you full details about her study.

If you **have experience in designing for autism and** are interested in getting more information about taking part in Wasan's study please read the brief description below and or CONTACT WASAN DIRECTLY by using her McMaster telephone number. Tel: 905-525-9140 **Ext:** or emails address **Nagibwf@mcmaster.ca** . The researcher will not inform OAA on who participated or not. Taking part or not taking part in this study will not affect your status or any services you receive at OAA.

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

McMaster Research Ethics Board Secretariat

Telephone: (905) 525-9140 ext. 23142

Gilmour Hall – Room 305 (ROADS)

E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Appendix A-3

Interview Schedule:

Semi-structured Interviews with Architects

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Masters Candidate)
Supervised by: Dr. Allison Williams

School of Geography and Earth Sciences

Information about these interview questions: These semi-structured interviews aim at acquiring additional insight on the physical elements that affect the quality of life of the autistic children and their families and the current trends in autism focused architecture to accommodate to their needs.

1) Participant Profile (Optional formation): Name? Place of employment? Years of experience?

2) Tell me about your experience in designing for autistics and, in particular, the home environment?

3) Do you think the current design trend for homes considers autistic needs?

[ ] Yes [ ] No Please explain your answer.

4) What are the most influential autistic behaviors that you try to address in your designs?

5) What are the most important architectural considerations that you implement in your designs?

6) What kind of modifications are requested by families of an autistic child? What is the average cost?

7) Do you think architecture for autism requires more research and investigation? Do you think a course about disability and, in particular for autism, should be included in the curriculum requirement for the architecture degree?

8) Is there something important that I have not asked you about? Is there anything else you think I need to know?

Appendix A-4

Interview Schedule:

Semi-structured Interviews with Occupational Therapists

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Masters Candidate)
Supervised by: Dr. Allison Williams

School of Geography and Earth Sciences

Information about these interview questions: These semi-structured interviews aim at acquiring additional insight on the daily challenges in home environment that affect the quality of life of autistic children and their families, physical elements that stimulate these challenges, treatment strategies, and current trends in occupational therapy toward enhancing the interaction of autistic children with their environment.

1) Participant Profile (Optional formation) : Name? Place of employment? Years of experience?

2) What percentage of occupational therapy takes place at the home?

3) Do you think the current home environment is suitable for conducting therapy or it needs modification? [ ] Yes [ ] No. Please explain your answer.

4) What are the most common autistic behaviors that you face during therapy?

5) Based on your experience, what kind of home modifications those need to take place to cope with these autistic behaviors?

6) What are the behavior elements that would be most responsive to modifications in the home environment?

7) Is there something important that I have not asked you about? Is there anything else you think I need to know?

Appendix A-4-a

Focus Group Interview Guide with Occupational Therapists

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Masters Candidate)
Supervised by: Dr. Allison Williams

School of Geography and Earth Sciences

Hello, my name is Wasan. Thank you for agreeing to have me in this focus group meeting. Just to remind everyone, I'm looking at acquiring additional insight on the daily challenges in home environment that affect the quality of life of autistic children and their families, physical elements that stimulate these challenges, treatment strategies, and current trends in occupational therapy toward enhancing the interaction of autistic children with their environment.

In a minute, we will all introduce ourselves – first names only. But first, I would like to walk you through the consent form that is in front of you.

Before we begin our discussion .I want to spend a few moments **talking about confidentiality** and to go over some basic ground rules for our focus group discussion today:

- Everyone's views are welcomed and important.
- The information which we will collect today will be attributable *(connected or associated)* to you as a group.
- We will not identify quotes or ideas *any one person* of this group. Because of the nature of small communities or groups, it is possible that people could link participants in this room to quotes in the report. This is why we need to talk about confidentiality.
- We *are* assuming that when we learn about one another's views, they remain confidential. In a small community (group) like this, people are identifiable to some degree by their views and opinions.
- Having said this, and having made these requests, you know that we cannot guarantee that the request will be honoured by everyone in the room.

- So we are asking you to make only those comments that you would be comfortable making in a public setting; and to hold back making comments that you would not say publicly.
- Anything heard in the room should stay in the room.
- All voices are to be heard, so I will step in if too many people are speaking at once or to make sure that everyone has a chance to speak.
- I may also step in if I feel the conversation is straying off topic. .
- You can expect this discussion group to last about 60-75minutes.

Use of Tape Recorder

- As you will recall, this focus/discussion group will be recorded to increase accuracy and to reduce the chance of misinterpreting what anyone says.
- All tapes and transcripts will be kept under lock and key .
- Names will be removed from transcripts. Participants will have coded numbers attached to their name which only I will know.
- Only I and (*my thesis supervisor Dr. Allison Williams)* will have access to transcripts (with personal names removed) of this focus group.
- For transcription purposes, I might remind you to say your first name for the first few times you speak so that when I'm transcribing the tape I can get used to recognizing your voice. That will ensure we assign the correct code to each person's answers. I will give you a gentle reminder.
- I'll also ask that when using abbreviations or acronyms, you say the full name at least once to aid transcription.
- We may also use a "flip chart" to write down key points during the focus group and take notes.

II. INTERVIEW

1) Participant Profile (Optional formation) : Name? Place of employment? Years of experience?

2) What percentage of the occupational therapy that you do takes place at the family home?

3) What are the most common autistic behaviors that you face during therapy?

4) Do you think the current home environment is suitable for conducting therapy in any way?

5) Based on your experience, what kind of home modifications need to take place in order to cope with these autistic behaviors?

6) What are the behavior elements that would be most responsive to modifications in the home environment?

7) Is there something important that I have not asked you about? Is there anything else you think I need to know ?

Appendix B-1:

Email Recruitment Script Sent to Families and caregivers on Behalf of the Researcher by Autism Ontario- Holder of the Participants' Contact Information

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Masters Candidate)
Supervised by: Dr. Allison Williams

School of Geography and Earth Sciences

Sample E-mail Subject line: McMaster study about Autism-friendly Home Environment

Dear Families,

Wasan Nagib, a McMaster student, has contacted Autism Ontario asking us to tell our members about a study she is doing on Autism-friendly Home Environments. The study explores the physical elements that affect the quality of life of autistic children and their families in home environment and how can these elements be designed (or modified) to create an autism-friendly home environment. The following is a brief description of here study. She is looking for families with an autistic child that has at least one sibling and has been living in their home for at least one year to take part in the study by completing an online Questionnaire posted on the link below. Completing the questionnaire will take approximately (15-20) minutes:

https://www.surveymonkey.com/s/6NCJV22

This research is part of her Master program in Geography at McMaster University. For more information about this study please contact: ***Wasan Nagib*** directly on her McMaster telephone number or email address. **Tel: 905-525-9140 Ext: 28617** or **Nagibwf@mcmaster.ca**.

Please note that the researcher will not inform me or anyone at Autism Ontario who participated or not. Taking part or not taking part in this study will not affect your status or any services you receive at Autism Ontario. The researcher has explained that you can stop being in the study at any time. In

addition, this study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

McMaster Research Ethics Board Secretariat

Telephone: (905) 525-9140 ext. 23142

Gilmour Hall – Room 305 (ROADS), E-mail: ethicsoffice@mcmaster.ca

Sincerely,

XX

Appendix B-2

Online Questionnaire
For families of children with autism

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Master Program)

Supervised by: Dr. Allison Williams

(School of Geography and Earth Sciences – McMaster University)

Information about this questionnaire: The aim of this questionnaire is to help analyzing the home environment where Canadian families with autistic children live. The questionnaire is designed to identify the most frequent challenging behaviors in home environment, critical elements of home environment that contribute to these challenges, common home environment modifications adopted (or recommended) by families to face the challenges and enhance their quality of life, and the cost incurred by families to modify their homes and the source of fund.

1) Family Profile:

1. Location:

	Country	If Canada, select province
Please Select		

2. Number of family members?

Please Select		

3. Age of the child with Autism:

   If more than one, please specify

4. Diagnosis of the Child on the Spectrum:

☐ Autism

☐ High Functioning Autism

☐ Asperger's Disorder

☐ Pervasive Developmental Disorder (PDD)

5. Please determine the severity, if known:

○ Mild ○ Moderate ○ Severe ○ None

2) Housing Profile:

1. Type of Housing:

○ Apartment ○ Attached House(Townhouse) ○ Detached House

2. Number of Rooms(excluding kitchen & bathroom):

3. Do you consider your home able to accommodate your child's needs?

○ Yes

○ No

○ Somewhat

4. How long have you been living in this home?

○ 0-1 year ○ 1-3 years ○ More than 3 years

5. Is there a private or a separable room for the child with autism?

Yes No

6. If your child gets therapy at home, where does it take place?

Child's bedroom Dedicated room

Living room No therapy

Other (please specify)

3-Challenges:

1. What are the challenges that you- or any family member- face with respect to having a child with autism at home?

Physical (for example, injury, damage to environment, lack of privacy) Psychological (for example, high level of stress, lack of time for other family members)

Social (for example, disturbance to neighbors, inability to invite family &friends, lack of social interaction) Other

4-Problems in the Home Environment:

What are the most disturbing sensory-related feature(s) of the home environment that stimulate your child's behavior?

1. Noise

	Noise from Outside	Noise from Inside
Noise		

Other (please specify)

2. Lighting:

☐ Sunlight ☐ Glare ☐ Flickering ☐ Dimmed light ☐ Other ☐ None

Other (please specify)

3. Color:

☐ Bright colors (red, orange, pink) ☐ Soft colors (blue, white, yellow) ☐ None

Other (please specify)

4. Disturbing visual features at home:

☐ Disturbed by cluttering

☐ Disturbed by outside scenes or activities

☐ Disturbed by indoor scenes of activities (from other rooms or family member)

☐ Disturbed by details or patterns (of furniture, walls, floor, etc.)

☐ Other

☐ None

Other (please specify)

5. Smell

☐ Indoor Smell ☐ Other

☐ Outdoor Smell ☐ None

Other (please specify)

6. Temperature

☐ Sensitivity to heat ☐ Sensitivity to cold ☐ None

5-Safety-related features in the Home Environment:

1. Do you think you need to see/supervise your child with autism most of the time?

○ Yes ○ No

2. Do you think that your child with autism is a threat?

○ Yes ○ No

3. If yes, please specify to whom/what :

☐ Self ☐ Family members ☐ Surrounding physical environment (for example, furniture) ☐ Other

Other (please specify)

4. Which space you consider to be MOST unsafe for your child with autism?

☐ Entrances ☐ Stairs ☐ Back yard

☐ Exit ways ☐ Bathroom ☐ Domestic appliances &

☐ Windows	☐ Swimming pool	equipments
☐ Kitchen	☐ Front yard	☐ Garage
		☐ Other

Other (please specify)

6-Behaviors:

1. What are the most common behaviors that triggered physical modifications in your home environment?

	First	Second	Third
Top 3 behaviors			

If other (please specify)

7-Modifications:

1. Have any modifications been done to your home to cope with these behaviors?

	Had to move to another place	Added a space to the current place	Architectural Elements	Interior Elements	Technology
Please selec					

t

If other or tools (please explain)

2. For who were the modifications made?

- [ ] Child
- [ ] Siblings
- [ ] Family
- [ ] Other

If other (please specify)

3. Are you satisfied with the results of these modifications? (Did it improve the quality of life of your child and the family?)

- ○ Yes
- ○ No
- ○ Somewhat

Please EXPLAIN

4. What is the estimated cost of these modifications?

- ○ None
- ○ $0-$500
- ○ $500-$1000
- ○ $1000-$3000
- ○ above $3000

5. How were these modifications funded?

☐ Private ☐ Institutional ☐ Governmental ☐ Other

If other (please specify)

8-Personal Satisfaction:

1. What modifications do you WISH to do but didn't or can't do?

2. Are you satisfied with your current home environment given your child's needs?

○ Yes

○ Somewhat

○ Not at all

If no, What do you wish to change?

3. In general, Do you think that the current design trends of homes and other buildings- consider the needs of people with autism?

○ Yes

○ Somewhat

○ No

*** YOU HAVE COMPLETED THE SURVEY***

Thank you so much for your participation!

If you know of someone that is also a parent/caregiver of a child with autism spectrum disorder (for example, a friend, parent/caregiver),Please don't hesitate to invite them to join this study by forwarding this link:
https://www.surveymonkey.com/s/6NCJV22

With regards,
Wasan Nagib
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext. 28167
E-mail: nagibwf@mcmaster.ca

1. Would you like to receive a summary of the study's results?

Yes

No

If Yes, Please provide your email or mailing address:

Appendix C-1

Email Recruitment Script for families and caregivers

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Master Program)

Supervised by: Dr. Allison Williams

(School of Geography and Earth Sciences – McMaster University)

Sample E-mail Subject line: McMaster study about Autism-friendly Home Environment

Wasan Nagib, a McMaster student, has contacted Autism Ontario asking us to tell our members about a study she is doing on Autism-friendly Home Environments. This research is part of her Master program in Geography at McMaster University. The study explores the physical elements that affect the quality of life of autistic children and their families in home environment and how can these elements be designed (or modified) to create an autism-friendly home environment. The following is a brief description of his study. She has asked us to attach a copy of her information letter to this email. That letter gives you full details about his study.

She is looking for families with an autistic child that has at least one sibling and has been living in their home for at least one year to take part in the study. The families will be asked to do the following:

1- Answering a brief list of questions through two interviews that will take place at family home. Each interview will take about 30-45 minutes. The time between the two interviews is two weeks
2- Recording home observations over 7 days following the first interview using a diary which will be provided to you. Your observation will focus on the challenges confronting the child and family members, while performing daily activities, due autism. For each incidence you will indicate where it takes place (which room), any space deficiency contributing to the challenges, the coping strategies you adopt and which physical modification of home environment are involved, and any suggested modifications to further enhance your quality of life. After that, the research will collect the diary from you and will discuss the observations in the second interview.

Participated families will receive a compensation of $ 100 in cash ($50 after the first interview and $50 after the second interview). If you are interested in getting more information about taking part in Wasan's study please read the brief description below and or **CONTACT WASAN DIRECTLY** by using her McMaster telephone number or email address. **Tel: 905-525-9140 Ext: 26187** or **Nagibwf@mcmaster.ca**. The researcher will not tell me or anyone at Autism Ontario who participated or not. Taking part or not taking part in this study will not affect Wasan has explained that you can stop being in the study at any time. In addition, this study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

McMaster Research Ethics Board Secretariat, Telephone: (905) 525-9140 ext. 23142,Gilmour Hall – Room 305 (ROADS). E-mail: ethicsoffice@mcmaster.ca

Appendix C-2

Interview for families of children with autism

Study title:

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib, (Master Program)

Supervised by: Dr. Allison Williams

(School of Geography and Earth Sciences – McMaster University)

1- **Information about these interview questions**: These interviews aim at exploring in-depth the lived experience of families with autistic children in the home environment and gets in touch with their daily challenges as a result of the inadequacy of the environment. In addition, this interview will allow a better understanding of how improving the home environment could enhance the quality of life of the families. The family will be asked to Record home observations over 7 days following the first interview using a diary. After that, the researcher will collect the diary from the family .The observations will be discussed with the researcher in the second interview.

1) Family Profile:
    a. Number of family members?
    b. Number and age of sibling(s)?
    c. Age of the autistic child?
    d. Diagnosis of the child on the spectrum? The severity if known? (For example, severe, mild, high functioning, Aspergers)
2) Housing Profile:
    a. Type of housing (apartment/detached home/townhouse)?
    b. Number of rooms?
    c. How long have you been living in this home?

d. Is there a private or separate room for the autistic child?
e. Does the child receive therapy at home?
    i. If yes where does it take place?

3) Child Profile:
    a. What are your child's sensory problems (sound-visual-odor-touch- temperature sensitivity)?
    b. What are your child's autism-related challenging behaviors in the home environment?
    c. What is the most unsafe space for the child in the home environment?
4) Daily Activities:
    a. What is the daily activity that your child with autism likes to do at home?
        i. Where does it take place?
        ii. Does the child share the space with others? Explain please.
        iii. What is your child's favorite space in the home environment?
5) Challenges for the family members:
    a. As a mother, what are the social challenges you are facing with having an autistic child at home? (For example, problem inviting visitors to the home, relationship with family members or others).
    b. Can you give some examples? Psychologically, do you think that having a child with autism increases the level of stress and frustration of family members?
        i. If yes, is it increasing as the child is growing up?
        ii. Being with the child at home, is it more or less stressful than taking him outside?
        iii. Are there any activities at home that you or any of your family members like but can't do because of having a child with autism?
        iv. What are the physical challenges experienced by the family with having a child with autism at home? (for example, injury, harm to the environment, lack of privacy).
        v. Please explain your daily routine.
6) Modifications:
    a. What kind of modifications were/have been done to your home environment?
    b. Can you tell me the story behind these modifications?
        i. At what age was the autistic child?

ii. Was there an accident that took place beforehand?
iii. Did the family have to move to another place?
iv. Did you have to add a space to the current place (i.e. extra room-backyard, other)
v. Did you change any architectural elements (i.e. window-fence-stairs-walls-other)
vi. Did you change any interior elements (i.e. furniture-lighting-landscape- color-other)
vii. Who is the reason behind these modifications? (Child, family, siblings, other)?

7) Impact of modifications on the quality of life:

a. Are you satisfied with these modifications? (Yes or No). Please tell me how these modifications improved the quality of life of your child and the family members. (What did it mean to the child and each of the family members?. Please explain.

b. Is there any additional modification you wish to do to enhance the quality of life of the child and-or the family members?

Appendix D-1

LETTER OF INFORMATION / CONSENT FOR ARCHITECTS

Study Title: Toward an Autism-friendly Home Environment

Student Investigator:

Wasan Fridon Nagib
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140
E-mail: nagibwf@mcmaster.ca

Faculty Supervisor:

Dr. Allison Williams
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140, Ext. 24334
E-mail: awill@mcmaster.ca

Purpose of the Study

I am doing this research as part of study for Master Degree in Human Geography. You are invited to take part in this study which aims at designing better homes for children with autism. To achieve this target I need your participation in defining the critical housing elements that affect the behavior of children with autism. I hope to learn how to design houses that not only convenient for family but also therapeutic for the children with autism.

What will happen during the study?

As an architect, who is evolved in designing for people with autism, you will participate to an interview where you will be asked about your experience on designing various buildings for these target users. You will be as asked also about specific design considerations for autism, your observations on the interaction of target users with the buildings and whether the design has achieved the objectives. I will also seek your advice related to designing autism-friendly residential environment. The interview will take place in your office (or in a mutually agreeable place). The interview will take about 20-30 minutes

and will be scheduled at a time that is convenient for you. With your permission, the interview will be audio-taped.

Are there any risks to doing this study?

Some of the questions may raise issues that you feel strongly about or that have generated frustrations for you. You do not need to answer any question you prefer to skip and can end your participation at any time. You may also worry about how others would react if they knew what you said. Please remember that you are participating confidentially. Your name and details will not be revealed in the study.

Are there any benefits to doing this study?

The result of this research will be of interest to families ,therapists and architects whom are looking forward to secure therapeutic living environment for the growing population of autistic children in Canada and worldwide. The result of the study can be used to inform the design of new homes as well as the assessment/evaluation and renovation of existing homes to be more autism-friendly.

Who will know what I said or did in the study?

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me (or other members of the research team) will know whether you participated unless you choose to tell them. Data will be securely kept in a locked drawer to which only I will have access. Once my study is completed I intend to keep the data for future research which I hope to conduct in the same area.

However, since your group (community) is small, others may be able to identify you on the basis of references you make. Please keep this in mind in deciding what to tell me.

What if I change my mind about being in the study?

You can withdraw from this study up until approximately [May, 2014], when I expect to be preparing the draft of my thesis. To do so you can contact me on the abovementioned email or phone number. In cases of withdrawal any data that you have provided will be destroyed unless you indicate otherwise

How do I find out what was learned in this study?

I expect to have this study completed by approximately *[September, 2014].* If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at:

nagibwf@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

CONSENT

- I have read the information presented in the information letter about a study being conducted by ***Wasan Fridon Nagib,*** of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time up until approximately ***May 2014*.**
- I have been given a copy of this form.
- I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____

1. I agree that the interview can be audio recorded.

Yes ……

No……..

2. Yes…… I would like to receive a summary of the study's results.

Please send them to this email address:

_____

Or to this mailing address:

_____

_____

_____

No…… I do not want to receive a summary of the study's results.

Appendix D-2-a

LETTER OF INFORMATION / CONSENT FOR OCCUPATIONAL THERAPISTS participating to focus group interview

Study Title: Toward an Autism-friendly Home Environment

Investigators:

Student Investigator:

Wasan Fridon Nagib
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140
E-mail: nagibwf@mcmaster.ca

Faculty Supervisor:

Dr. Allison Williams
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140, Ext. 24334
E-mail: awill@mcmaster.ca

Purpose of the Study

I am doing this research as part of study for Master Degree in Human Geography. You are invited to take part in this study which aims at designing better homes for children with autism. To achieve this target I need your participation in defining the critical housing elements that affect the behavior of children with autism. I hope to learn how to design houses that not only convenient for family but also therapeutic for the children with autism.

What will happen during the study?

As an occupational therapist working with autistic children in home environment you will be asked through a focus group interview regarding challenges in home environment that affect the quality of life

of autistic children and their families, physical elements that stimulate these challenges, treatment strategies, and current trends in occupational therapy toward enhancing the interaction of autistic children with their environment. The interview will take place in your office/clinic (or in a mutually agreeable place). The focus group interviews will take about 60-75 minutes and will be scheduled at a time that is convenient for you. With your permission, the interview will be audio-taped.

Are there any risks to doing this study?

Some of the questions may raise issues that you feel strongly about or that have generated frustrations for you. You do not need to answer any question you prefer to skip and can end your participation at any time. You may also worry about how others would react if they knew what you said. Please remember that you are participating confidentially. Your name and details will not be revealed in the study.

Are there any benefits to doing this study?

The result of this research will be of interest to families ,therapists and architects whom are looking forward to secure therapeutic living environment for the growing population of autistic children in Canada and worldwide. The result of the study can be used to inform the design of new homes as well as the assessment/evaluation and renovation of existing homes to be more autism-friendly.

Who will know what I said or did in the study?

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me (or other members of the research team) will know whether you participated unless you choose to tell them. Data will be securely kept in a locked drawer to which only I will have access. Once my study is completed I intend to keep the data for future research which I hope to conduct in the same area.

However, since your group (community) is small, others may be able to identify you on the basis of references you make. Please keep this in mind in deciding what to tell me.

What if I change my mind about being in the study?

You can withdraw from this study up until approximately [May, 2014], when I expect to be preparing the draft of my thesis. To do so you can contact me on the abovementioned email or phone number. In cases of withdrawal any data that you have provided will be destroyed unless you indicate otherwise

How do I find out what was learned in this study?

I expect to have this study completed by approximately *[September, 2014].* If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at:

nagibwf@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

CONSENT

- I have read the information presented in the information letter about a study being conducted by ***Wasan Fridon Nagib,*** of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time up until approximately ***May 2014*****.**

- I have been given a copy of this form.
- I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____

1. I agree that the interview can be audio recorded.

Yes ……

No……..

2. Yes…… I would like to receive a summary of the study's results.

Please send them to this email address:

_____

Or to this mailing address:

_____

_____

_____

No…… I do not want to receive a summary of the study's results.

DATE: _____

Appendix D-2-b

LETTER OF INFORMATION / CONSENT FOR OCCUPATIONAL THERAPISTS participating in individual interviews

Study Title: Toward an Autism-friendly Home Environment

Investigators:

Student Investigator:

Wasan Fridon Nagib
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140
E-mail: nagibwf@mcmaster.ca

Faculty Supervisor:

Dr. Allison Williams
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140, Ext. 24334
E-mail: awill@mcmaster.ca

Purpose of the Study

I am doing this research as part of study for Master Degree in Human Geography. You are invited to take part in this study which aims at designing better homes for children with autism. To achieve this target I need your participation in defining the critical housing elements that affect the behavior of children with autism. I hope to learn how to design houses that not only convenient for family but also therapeutic for the children with autism.

What will happen during the study?

As an occupational therapist working with autistic children in home environment you will be asked , through a one-to-one interview, regarding challenges in home environment that affect the quality of life of autistic children and their families, physical elements that stimulate these challenges, treatment strategies, and current trends in occupational therapy toward enhancing the interaction of autistic

children with their environment. The interview will take place in your office/clinic (or in a mutually agreeable place). The one-to-one interview is expected to take 20-30 minutes. The interviews will be scheduled at a time that is convenient for you. With your permission, the interview will be audio-taped.

Are there any risks to doing this study?

Some of the questions may raise issues that you feel strongly about or that have generated frustrations for you. You do not need to answer any question you prefer to skip and can end your participation at any time. You may also worry about how others would react if they knew what you said. Please remember that you are participating confidentially. Your name and details will not be revealed in the study.

Are there any benefits to doing this study?

The result of this research will be of interest to families ,therapists and architects whom are looking forward to secure therapeutic living environment for the growing population of autistic children in Canada and worldwide. The result of the study can be used to inform the design of new homes as well as the assessment/evaluation and renovation of existing homes to be more autism-friendly.

Who will know what I said or did in the study?

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me (or other members of the research team) will know whether you participated unless you choose to tell them. Data will be securely kept in a locked drawer to which only I will have access. Once my study is completed I intend to keep the data for future research which I hope to conduct in the same area.However, since your group (community) is small, others may be able to identify you on the basis of references you make. Please keep this in mind in deciding what to tell me.

What if I change my mind about being in the study?

You can withdraw from this study up until approximately [May, 2014], when I expect to be preparing the draft of my thesis. To do so you can contact me on the abovementioned email or phone number. In cases of withdrawal any data that you have provided will be destroyed unless you indicate otherwise

How do I find out what was learned in this study?

I expect to have this study completed by approximately *[September, 2014].* If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at:

nagibwf@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

CONSENT

- I have read the information presented in the information letter about a study being conducted by ***Wasan Fridon Nagib,*** of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time up until approximately ***May 2014*.**
- I have been given a copy of this form.
- I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____

1. I agree that the interview can be audio recorded.

Yes ……

No……..

2. Yes…… I would like to receive a summary of the study's results.

Please send them to this email address:

_____

Or to this mailing address:

_____

_____

_____

No…… I do not want to receive a summary of the study's results.

Appendix D-3

LETTER OF INFORMATION / CONSENT FOR FAMILIES PARTICIPATING IN ONLINE QUESTIONNAIRE

Study Title: Toward an Autism-friendly Home Environment

Investigators:

Student Investigator:

Wasan Fridon Nagib
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140
E-mail: nagibwf@mcmaster.ca

Faculty Supervisor:

Dr. Allison Williams
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140, Ext. 24334
E-mail: awill@mcmaster.ca

Purpose of the Study

I am doing this research as part of study for Master Degree in Human Geography. You are invited to take part in this study which aims at designing better homes for children with autism. To achieve this target I need your participation in defining the critical housing elements that affect the behavior of children with autism. I hope to learn how to design houses that not only convenient for family but also therapeutic for the children with autism.

What will happen during the study?

If you are a parent of a child with autism that has at least one sibling and has been living in the same home for at least one year, you can take part in this study by filling an online questionnaire including basic information about your child with autism and family members, his/her behaviour in home environment, your observations on the impact of various housing elements on autism related behaviours. By clicking on "I agree and welling to fill the online questionnaire", at the end of this statement, you will be directed automatically to start the questionnaire. It is expected to take approximately 20-15 minutes to complete the questionnaire.

Are there any risks to doing this study?

Some of the questions may raise issues that you feel strongly about or that have generated frustrations for you. Despite that your answers for all questions are very valuable for the porpose of this study, you do not need to answer any question you prefer to skip and can end your participation at any time. Please also note that your privacy is fully preserved. You are not asked to reveal your identity (name, address, telephone number, occupation), or any information that would allow you to be identified.

.

Are there any benefits to doing this study?

The result of this research will be of interest to families ,therapists and architects whom are looking forward to secure therapeutic living environment for the growing population of autistic children in Canada and worldwide. The result of the study can be used to inform the design of new homes as well as the assessment/evaluation and renovation of existing homes to be more autism-friendly

Who will know what I said or did in the study?

No one but I and my supervisor will know the information you provided. Online data will be secured by password and print-outs will be kept in a locked drawer. I will be the sole person who can access this data. Once my study is completed I intend to keep the data for future research which I hope to conduct in the same area.

However, since your group (community) is small, others may be able to identify you on the basis of references you make. Please keep this in mind in deciding what to tell me.

What if I change my mind about being in the study?

You can withdraw from this study up until approximately [May, 2014], when I expect to be preparing the draft of my thesis. To do so you can contact me on the abovementioned email or phone number. You should provide me with the unique participation number which appears at the top of the screen while you are filling the questionnaire. Please keep this number for your reference. In cases of withdrawal any data that you have provided will be deleted unless you indicate otherwise

How do I find out what was learned in this study?

I expect to have this study completed by approximately *[September 2014].* If you would like a brief summary of the results, please contact me on the abovementioned email or phone number and advice me on how to send you the brief.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at:

nagibwf@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

CONSENT

- I have read the information presented in the information letter about a study being conducted by ***Wasan Fridon Nagib,*** of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time up until approximately ***May 2014*****.**

If you agree on the contents of this introductory statement and willing to fill the on-line questionnaire please click here.	**I agree** and willing to fill the questionnaire
If you disagree and want to leave this page please click here and you will be directed to your homepage	**I disagree**

Appendix D-4

LETTER OF INFORMATION / CONSENT FOR FAMILIES PARTICIPATING IN DIARY INTERVIEWS

Study Title: Toward an Autism-friendly Home Environment

Student Investigator:

Wasan Fridon Nagib
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140
E-mail: nagibwf@mcmaster.ca

Faculty Supervisor:

Dr. Allison Williams
Department of Geography and Earth Science
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140, Ext. 24334
E-mail: awill@mcmaster.ca

Purpose of the Study

I am doing this research as part of study for Master Degree in Human Geography. You are invited to take part in this study which aims at designing better homes for children with autism. To achieve this target I need your participation in defining the critical housing elements that affect the behavior of children with autism. I hope to learn how to design houses that not only convenient for family but also therapeutic for the children with autism.

What will happen during the study?

If you are a parent of a child with autism that has at least one sibling and has been living in the same home for at least one year, you may take part in the diary\interview where you will be asked to answer a brief list of questions over two interviews that will take place at your home. Each interview will take about 30-45 minutes and will be scheduled at a time that is convenient for you. The time between the

two interviews is two weeks. Following the first interview will be asked to record home observations over 7 days using a diary which I will provide. Your observation should focus on the challenges confronting the child and family members, while performing typical daily activities due autism. For each incidence I will be interested to know where it takes place (which room), any space deficiency which may contribute to the challenges, the coping strategies you adopt and which physical modification of home environment are involved, and any suggested modifications to further enhance your quality of life. After that, I will collect the diary from you and we will discuss the observations in the second interview. With your permission, The interviews will be audio-taped.

Are there any risks to doing this study?

Some of the questions may raise issues that you feel strongly about or that have generated frustrations for you. You do not need to answer any question you prefer to skip and can end your participation at any time. You may also worry about the loss of privacy involved in my coming into your home and having pictures you have taken. Please remember that you are participating confidentially. I describe below the steps I am taking to protect your privacy:

a) Real names and detailed addresses will not be revealed in the study.
b) Visits will be organized in convenient time for families
c) Photos will be immediately anonymized by blurring any faces that appear or anything else that might allow the participants to be identified.

Are there any benefits to doing this study?

The result of this research will be of interest to families ,therapists and architects whom are looking forward to secure therapeutic living environment for the growing population of autistic children in Canada and worldwide. The result of the study can be used to inform the design of new homes as well as the assessment/evaluation and renovation of existing homes to be more autism-friendly

Is there any compensation for participating to this study?

Participated families will receive a compensation of $ 100 in cash ($50 after the first interview and $50 after the second interview)

Who will know what I said or did in the study?

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me (or other members of the research team) will know whether you participated unless you choose to tell them. Collected materials will be securely kept in a locked drawer to which only I will have access. Once my study is completed I intend to keep the data for future research which I hope to conduct in the same area.

However, since your group (community) is small, others may be able to identify you on the basis of references you make. Please keep this in mind in deciding what to tell me.

What if I change my mind about being in the study?

You can withdraw from this study up until approximately [May, 2014], when I expect to be preparing the draft of my thesis. To do so you can contact me on the abovementioned email or phone number. In cases of withdrawal any data that you have provided will be destroyed unless you indicate otherwise. You withdrawal from the study will not affect any compensation you have already received

How do I find out what was learned in this study?

I expect to have this study completed by approximately *[September 2014].* If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at:

nagibwf@mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

CONSENT

- I have read the information presented in the information letter about a study being conducted by ***Wasan Fridon Nagib,*** of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time up until approximately ***May 2014*.**
- I have been given a copy of this form.
- I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____

1. I agree that the interview can be audio recorded.

Yes ……

No……..

2. Yes…… I would like to receive a summary of the study's results.

Please send them to this email address:

_____

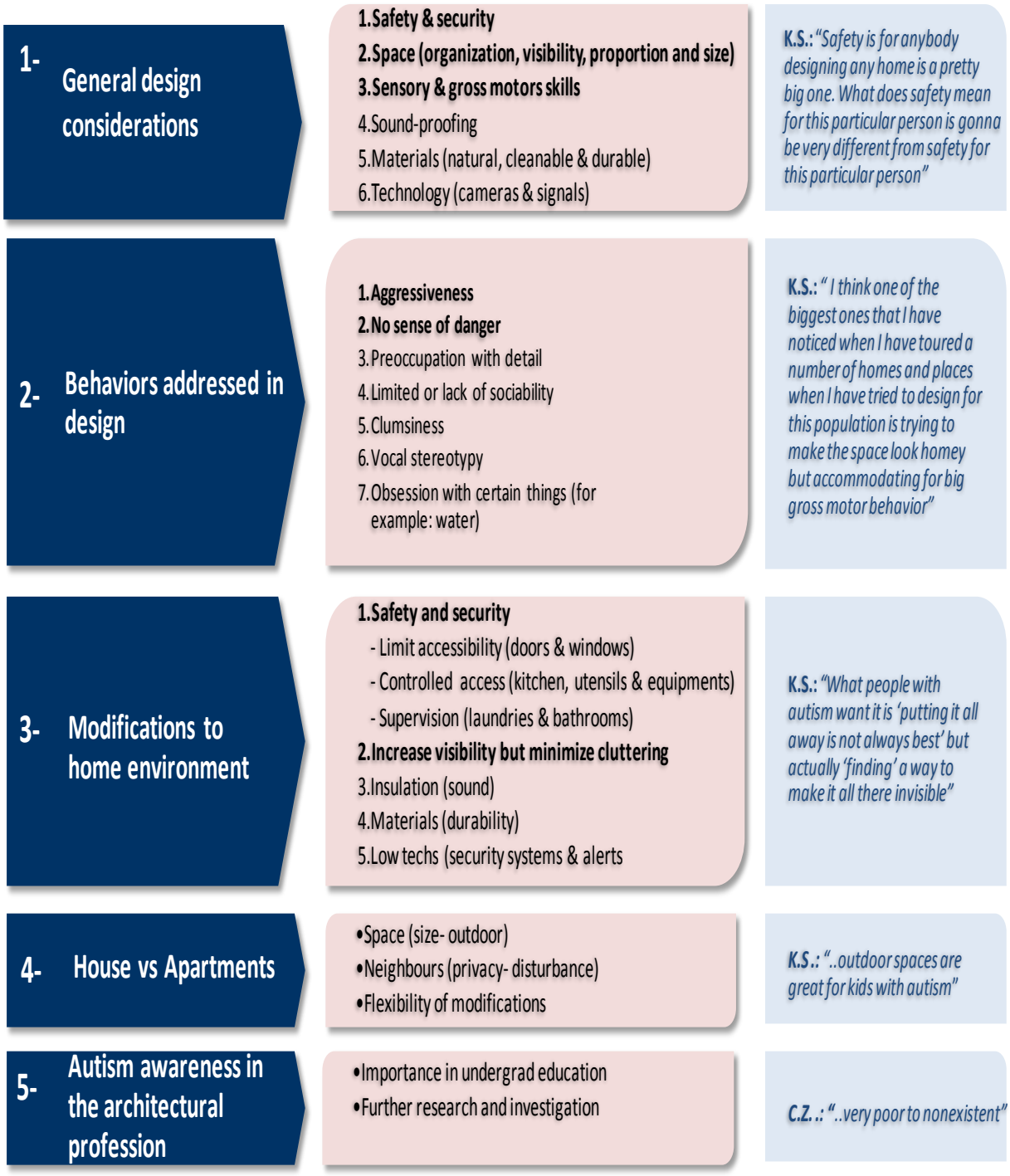
Or to this mailing address:

_____

No…… I do not want to receive a summary of the study's results.

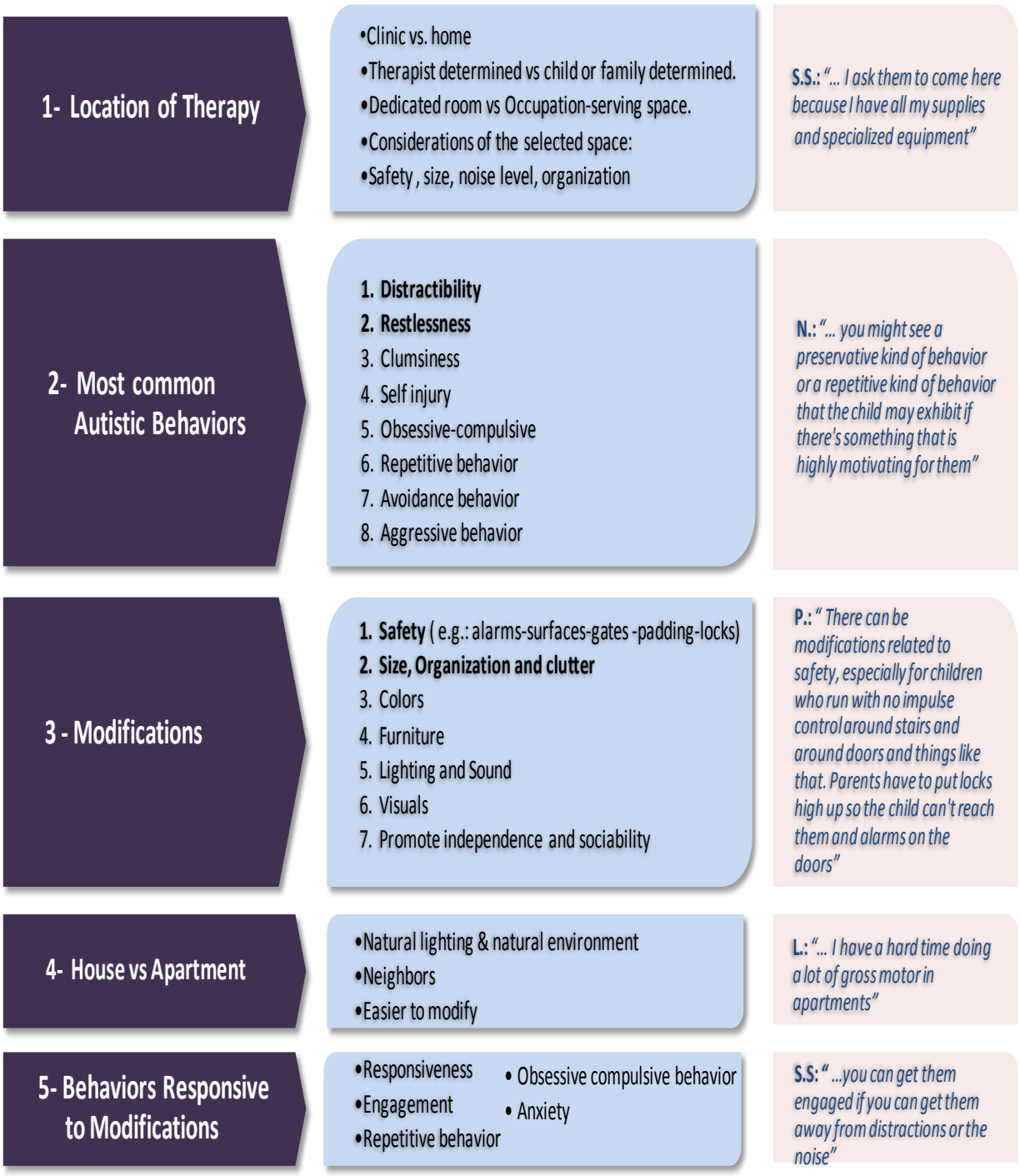
Appendix E-1

Themes and Subthemes: Architects



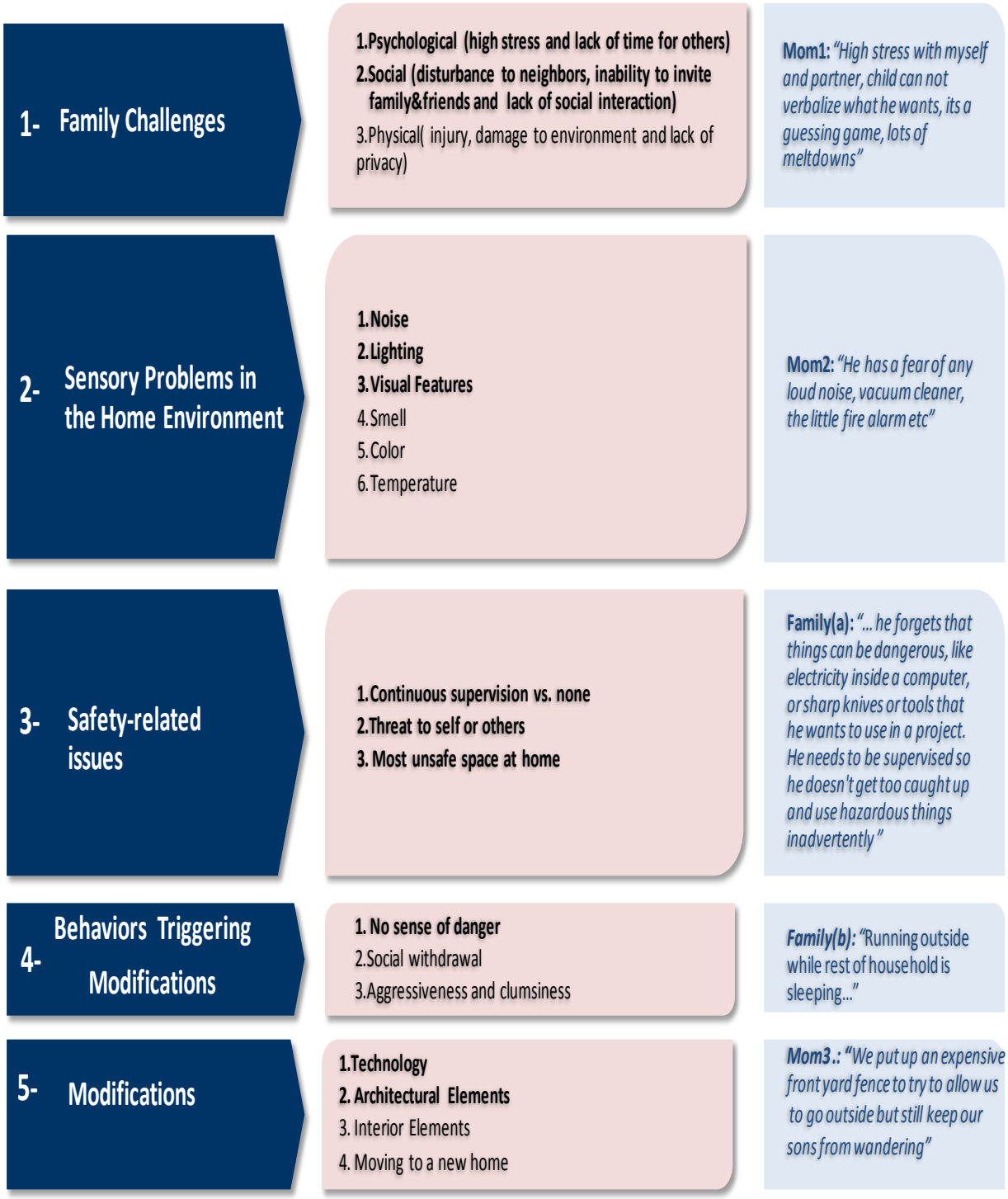
Appendix E-2

Themes and Subthemes: Occupational Therapists



Appendix E-3

Themes and Subthemes: Online Questionnaire



Appendix E-4

Themes and Subthemes: Diary-Narrative Interview with Selected Cases

Appendix F

Criteria for Rigour in the Research

Criteria and Definition	**Practices to satisfy criteria as used in this research**
Credibility-Authentic representations of experience	• Purposeful sampling of participants. • Data triangulation using interviews, structured survey questionnaire, and observations • The use of clarifying questions, taping and transcribing the interviews and returning them to the participants to amend if required • Involvement of peer review in design, conducting & analysis of data • Member checking to ensure agreement of representative of data. Data was also illustrated by quotes
Transferability-Fit within the contexts outside the study situation	• Thick description by providing background data on the context of the study and a detailed description of the methodological strategies to allow comparisons to be made
Dependability-Minimization of idiosyncrasies in interpretation. Variability tracked to identifiable sources	• In-depth methodological description to allow similar studies to be repeated in another context • Member checking • Debriefing
Confirmability-Extent to which biases, motivations, interests or perspectives of the inquirer influence interpretation	• Triangulation to reduce influence of researcher bias • Acknowledgement of researcher's beliefs and assumptions • In-depth methodological description to allow the checking of the research results • Use of diagrams, providing an audit trail
Reliability	• Mechanically recorded data • Member checking • Triangulation, inquiry audit
Validity	• Purposeful sampling • Triangulation • Referential adequacy • Member checking • Thick description

Source: Lincoln & Guba (1985) as in Baxter and Eyles, 1997

Appendix G

Lay report

Study Title: Toward an Autism-friendly Home Environment

Wasan F. Nagib
School of Geography and Earth Sciences

What was the purpose of my research?

The purpose of my research was to help families and professionals (architects and occupational therapists) in the creation of a home environment that responds not only to the needs of children with autism, but also the families with whom they live. To achieve this target, it was important to understand the challenges faced by children with autism and their families in the home environment, and how the physical elements of the home environment can be designed or modified to alleviate these challenges and create an autism-friendly home.

How was the research conducted?

Data for this research was gathered through interviews with professionals experienced in creating or modifying the home environment to make it autism-friendly, including 4 architects and 11 occupational therapists (OTs). An online questionnaire was also conducted to learn from families with children with autism living in various housing types across Canada and the USA (detached house, townhouse, and apartment). The number of participant families was 168. Finally, three families with children with autism (representing each of the three housing types) was interviewed. These interviews explored each families' lived experience and, how their quality of life was affected by the housing modifications that had been made. The data was then analyzed to understand: the most common challenges facing families in the home environment; the common physical modifications adopted to alleviate the challenges, and; the impact these modifications had on the physical, psychological and social wellbeing of all family members.

What were the major findings?

Architects emphasized sensory challenges, together with social and communication, and behavioral challenges, when designing homes for families. Occupational therapists also defined a list of autism-related behaviors associated with a deficient home environment, with distractibility at the top of the list, followed by restlessness. Occupational therapists recommended four types of modifications related to: mobility; safety; space organization, and; sensory challenges. Interestingly, the architects and occupational therapists that were interviewed did not mention the challenges faced by family members (parents and siblings) living with a child with autism as a reason for modifying the home environment. They focused mostly on the needs of the child with autism. This important finding suggests that research on creating an autism-friendly home environment should be multi-disciplinary, where a holistic understanding of the needs of all family members is essential. Interviews with architects also revealed the lack of attention to designing for the disabled in the profession and in the training of architects. This has resulted in a dearth of disability-friendly designs in general, and designs for autism in particular.

According to the results of the online questionnaire, 87% of the respondents noted that sensitivity to noise was the most common sensory problem among children with autism, followed by visual sensitivity (67%), sensitivity to lighting (66%), temperature (54%), and colors (20%). The lack of a sense of danger was the most common behavior that triggered home modifications, as reported by 53% of the respondents, followed by tantrums (28%) and aggression (24%). Psychological and emotional challenges (e.g., stress, embarrassment, and depression) were experienced by 76% of the parent participants, followed by social challenges (e.g., isolation from friends and community, marital unhappiness, poor relationship with neighbors, and loss of career). Physical challenges (e.g., destruction of household items, injuries to siblings and parents, and exhaustion) were reported by 43% of the parents. Siblings felt abandoned and less loved due to their parents being mostly busy with their child with autism.

Various modifications to the home environment were implemented by the families included in the study. The majority (81%) of modifications were primarily to deal with a challenge related to the child with autism, while 16% targeted the siblings. Three main categories of modifications were identified: (1) creation of extra space either by moving to a larger home (27%) or by adding space

to the existing home (40%); (2) modifications to the existing space, such as addition of safety measures (e.g., gates, fence) (35%) and space re-organization (e.g., adding storage to reduce clutter) (24%),and; (3) use of technological tools to enhance safety (e.g., locks and alarm systems) (67%). Four characteristics specific to the single-family housing typology rendered this typology as favorable for families with a child with autism: (1) larger unit size; (2) less proximity to neighbors; (3) more flexibility for adaptation; and (4) more outdoor space. From the interviews with the families, it became evident that home modifications positively affected their experience of the home as an occupational, social, emotional, symbolic, and personal space.

What are the major recommendations?

The study identified the most important design principles affecting the physical, social, and symbolic environment, suggesting the following therapeutic design matrix:

	Whole family	Child with ASD	Parents	Siblings
Physical Environment	- Safety (indoor & outdoor) - Provide larger space for all - Accessibility to outdoor. - Choose a quiet neighborhood	- Sensory controlled environment - Accommodating gross-motor equipments - Freedom of movement - Space for therapy - Space for play - Flexibility to accommodate future needs	- Maximize space visibility to ease supervision - Using cleanable and durable materials to ease household management - Provide stress relieving environment	- Space separation
Social Environment	- Reduce negative impacts to and from neighbors - Promote family gathering activities - Zonable (multi-use) interior space	- Promote independence. - To be with the group but not in focus - Space to retreat from overwhelming social situations	- Max. visibility to ease supervision - Privacy for marital space - Establishing boundaries for social activities - Expandability for future	- Capacity to host friends - More parental attention
Symbolic Environment	- Promoting Sense of at-homeness	- Promoting identity (personalization) - Symbolizing activities and spaces	- Promoting sense of relaxation and control	

The matrix provides a framework to encourage home design strategies to achieve the stated design principles while also suggesting a modification plan for a certain households. The matrix can be used as a tool to inform policy makers in developing building codes and design guidelines for autism.