Transitional Support System

for Children's Treatment Centres

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ABSTRACT

This study aimed to understand how a transitional support system can help children with NDD/D to minimize the behavioural and emotional challenges generated by transitions when visiting a treatment centre. In order to comprehend children with NDD/D, parents/caregivers, and health professionals perspectives, this study relied on qualitative and quantitative research methods. Firstly, observations helped to determine the correlation between transitions and challenging behaviours/emotions when visiting the treatment centre. Secondly, literature review provided evidence-based resources about children's development, neurodevelopmental disorders and disabilities, parents/caregivers' perspectives, children's treatment centres, and health professionals' role. Thirdly, semi-structured interviews promoted the knowledge of lived experiences and perspectives about treatment centres environments. Finally, a co-design session supported the identification of processes and the impact level of transitions throughout the visit to the treatment centre.

This study concluded that visiting a treatment centre is a two-phase process characterized with a series of steps and transitions that present different levels of behavioural and emotional challenges in children with NDD/D. Additionally, it identified that each step in the process should keep an adequate level of connectivity, continuity, and consistency to be effective and promote positive experiences for children with NDD/D and their parents/caregivers. Finally, the development of a transitional support system for children with NDD/D can help to create a secure and comfortable environment that will enhance better treatment results and well-being for them and their parents/caregivers.

ACKNOWLEDGEMENT

DEDICATION

To the amazing children, parents/caregivers, and health professionals that inspired this project.

To my best friend and beloved husband, Carlos Y. Thank you for being the source of inspiration, trust, and love that fulfills and guides my life.

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COLLABORATION

This research collaboration emerged as a response to Grandview Kids' interest in partnering with the Master of Design in Inclusive Design Program at OCAD University to develop design research and strategies for the new Grandview Kids building in Ajax, Ontario. As a result of the collaboration, *The Sensory Design Guidelines: Inclusive Children's Treatment Centres* (Pui Yee Nikkie To) and the *Transitional Support System for Children's Treatment Centres* (Grace Mendez) were developed to be complementary documents to aid in the development of new buildings, the renovations of existing buildings, and the implementation of support systems to better serve special needs children and youth.

CHAPTER 1: INTRODUCTION

Problem Statement

Rous, Teeters Myers, & Buras Stricklin (2007) states that transitions involve a process of movement or shift from one environment to another and are an important part of human life, from infancy to adulthood. Transitions demand changes that often can produce challenging behaviours and emotions in individuals. For instance, children are more susceptible to experiencing difficult transitions as a response to changes in their environment or routines. To overcome the uncertainty and cope with challenging behaviours and emotions, children rely on the support and guidance of their parents/ caregivers. Several studies had focused on children's diverse abilities and their responses to change. However, there is not enough knowledge about the effects of transitions in children with neurodevelopmental disorders and disabilities (NDD/D), especially when visiting a treatment centre.

Children's treatment centres are constant recurring context in children with NDD/D and their families' lives, as they aim to support their development and well-being. They offered a range of services such as Occupational Therapy, Physiotherapy, Speech-Language Pathology, Therapeutic Recreation, Audiology, Infant Hearing, Blind Low Vision, Social Work, and Autism Program. Although these spaces might seem familiar, visits can produce challenging behaviours and emotions in children with NDD/D. To gain a fuller understanding of which transitions generate challenging effects in children when visiting a treatment centre, in-depth qualitative and quantitative research is required. Focusing on children with NDD/D, parents/caregivers, and health professionals' experiences can help to develop robust knowledge of transitions when visiting a treatment centre, as well as potentially developing a toolkit that can help children with NDD/D to overcome its effects.

CHAPTER 1:
INTRODUCTION

This study aims to understand children with NDD/D's experiences when visiting a treatment centre and identify difficult transitions throughout their journey. Furthermore, this project aims to develop resources that can help minimize challenging effects, enhance treatments' outcomes, and create positive experiences for children with NDD/D and parents/caregivers. Through observations, semi-structured interviews, and co-design sessions, this study gained in-depth insight into the children with NDD/D, parents/caregivers, and health professionals' perceptions and experiences.

Research Questions

How can a transitional support system help children with NDD/D minimize the behavioural and emotional challenges generated by transitions when visiting a treatment centre?

How can a transitional support system promote a secure environment that empowers children with NDD/D's independence and well-being?

How can a transitional support system become an ally for parents/caregivers and health professionals that reduces time and effort when preparing the child for the visit or the treatment session?

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Key Terms

Behavioural and emotional challenges: Among children with NDD/D, behavioural and emotional problems are commonly encountered and are associated with significant impact on the health and well-being of children and their families. Common concerns are Attention, Concentration and Distractibility, Anxiousness, Shyness, and Emotional Sensitivity, Social Isolation/Peer Engagement, Tantrums/ Outbursts/Meltdowns, Volatility/ Self-regulation Difficulties, Sensory Issues, Inflexibility/Gets Stuck or Fixated, and Social Behaviours (Miller, Gardiner, & Harding, 2018).

Child: A person 19 years or younger unless national law defines a person to be an adult at an earlier age. WHO defines a child as a person 1–9 years of age (Hamadache & Clayden, 2018)

Children with Neurodevelopmental Disorders/Disabilities (NDD/D): A group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour (Morris, Janssens, Tomlinson, Williams, & Logan, 2013).

Children's Treatment Centres: Organizations that provide services in the ecosystem of child development and rehabilitation supports for children with special needs and their families. They provide a range of child development and rehabilitation services based on the needs of the community (EKO, 2020).

Health Professionals: Health professionals play a central and critical role in improving access and quality health care for the population. They provide essential services that promote health, prevent diseases and deliver health care services to individuals, families and communities (WHO, 2020).

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Journey: An act or instance of traveling from one place to another (Merriam-Webster, 2020).

Parents/Caregivers: A caregiver is the person who looks after infants and young children. The care of young children is not limited to parents. Infants and young children frequently have several key caregivers such as other relatives, siblings and friends (WHO, 2004).

Security & Comfort: A child who is secure and comfortable actively explores the environment (WHO, 2004).

Transitions: A process of movement or shift from one environment to another. It requires change, brings new opportunities and challenges, and often is regarded as stressful (Rous, Teeters Myers, & Buras Stricklin, 2007).

Transitional Support System (TSS): Set of tools that aim to support children with NDD/D to minimize the behavioural and emotional challenges generated by transitions.

TSS Tools: Objects developed to meet an specific objective based on the requirements of the individuals and the environment.

Well-being: the state of being happy, healthy, or prosperous (Merriam-Webster, 2020).

CHAPTER 2: LITERATURE REVIEW

Understanding Disabilities

Disability is a term that denotes a physical or mental condition that prevents individuals from performing at their full potential. According to the World Health Organization (WHO), disability is currently considered a societal issue rather than only relatable to an individual. Therefore, the interest in promoting social change and developing inclusive solutions that can help to remove barriers (WHO, 2010). Part of this new perception is WHO's International Classification of Functioning, Disability, and Health (ICF), released in 2001, which focuses on understanding disability from a holistic perspective instead of as a result of a health problem. Therefore, it conceptualizes disability as a "dynamic interaction between a person's health condition, environmental factors, and personal factors" (WHO, 2001).

Understanding Children's Development and Neurodevelopmental Disorders and Disabilities (NDD/D)

The WHO states that "children and youth development relates to their growth in the areas of human functioning (social and emotional, cognitive, communication and movement), are age-specific and are influenced by physical as well as psychological factors in the environment" (WHO, 2007). This vision is supported by "the conceptualization of child development model" (Ertem, 2011), which "postulates that human development takes place through progressively more complex interactions between a "biopsychosocial" human being and the persons, objects, symbols and systems in his or her proximal and distal environment. This interaction is dynamic and the child plays an active role from birth onwards" (WHO & UNICEF, 2012).

CHAPTER 2:

LITERATURE REVIEW
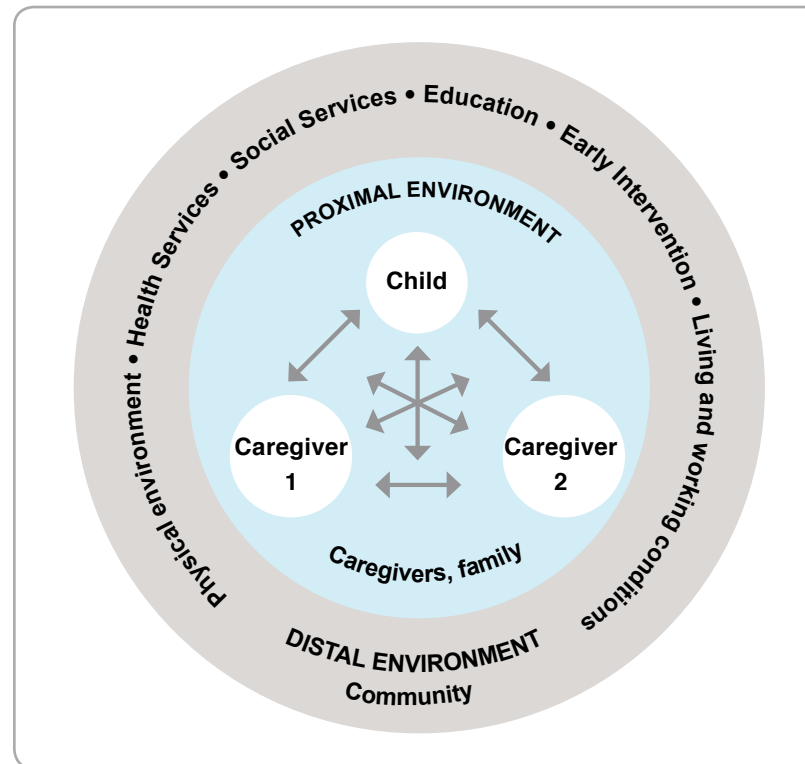
Figure 1.
Conceptualization of child development
(reproduced from Ertem, 2011)

According to the American Academy of Pediatrics (AAP), children's developmental stages are classified in four groups: infants (birth through 11 months), early childhood (1-4 years old), middle childhood (5-10 years old), and adolescence (11- 21 years old) (American Academy of Pediatrics, 2017).

In infancy, "the quality of the everyday actions of the parents – smiling, talking, cuddling, singing, and responding to the infant – shapes the circuitry of the developing brain" (Shore, 1997; Hannon, 2003). Consequently, infants' cognitive, physical, social, and emotional development relies on the interactions generated by their parents/caregivers. In the case of any change in infants' health conditions, parents/caregivers rely on the expertise of health professionals, as they will be able to guide them and offer extra support in the case of disabilities (American Academy of Pediatrics, 2017).

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In early childhood, similar to in infancy, children's development depends on child-parent/caregiver interactions along with the support of health professionals. In this stage, children become more physically active (e.g. walking), extra curious about their surroundings, and develop linguistics as they start naming things and communicating wishes and feelings. AAP affirms that "children need access to a variety of tools (books and toys) and experiences." Parents/caregivers start creating routines and rules that "may help reduce continual developmental stresses common to this age," and promote engaging activities that "accentuates the child's strengths and achievements." (American Academy of Pediatrics, 2017).

In middle childhood, children move towards independence and growth in their self-esteem. In this stage, children step outside of the family environment and start to explore the educational system. They begin to socialize, "assume self-care responsibilities," have a more prominent perception of their actions and their consequences in others and the new environment. Parents/caregivers' support is indispensable for children to cope with these transitions along with health professionals in the case of delays that may present during this period of growth (American Academy of Pediatrics, 2017).

Adolescence is considered a considerable transitional stage as it opens the door to adulthood. Adolescents have to embrace physical, psychological, and social challenges that appear at different intensities throughout this phase. Considering that the cognitive, social and emotional, communicational, and physical development is at the last stage of childhood, the support provided to adolescents should focus on becoming independent, active, self-sufficient, and productive individuals. Good and stable relations between parents/caregivers and adolescents is necessary to manage the stress and uncertainty that this phase may bring. Additionally, assistance from health professionals is valuable, especially in the encounter of any delays (American Academy of Pediatrics, 2017).

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WHO, UNICEF & AAP agree that children's development and growth depend on the support and surveillance of parents/caregivers and health professionals. Their teamwork is indispensable to achieve milestones according to their age, clarify information, and access services promptly. WHO states that "any change in the body functions, structures or performance of expected developmental skills define the concept of developmental delay and often serve as the basis for identifying children and youth with an increased risk of disabilities" (WHO, 2007). Early detection and intervention can minimize negative effects on children's development and help them to live their lives to the best of their abilities (American Academy of Pediatrics, 2017).

Several studies have recognized a "consensus-based" definition of neurodisability conceived from the perspectives of parents of children with neurological conditions and health professionals. It describes neurodisability as "a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour" (Morris, Janssens, Tomlinson, Williams, & Logan, 2013).

Similarly, Miller et al. states that "children with neurodevelopmental disorders/disabilities (NDD/D) or "neurodisability" are the largest identifiable subpopulation of children with disabilities. NDD/D comprise an array of conditions characterized by impairment in posture-mobility, cognitive-adaptive functioning, communication, relating socially, and regulating emotions and behaviour; biological or physical markers of a specific medical condition may or may not be present. Diagnoses under NDD/D include autism spectrum disorders (ASD), intellectual or learning disabilities, attention-deficit/hyperactivity disorder (ADHD), cerebral palsy, and Down and fetal alcohol syndromes" (A. Miller et al., 2016).

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Understanding the Parents/Caregivers' Perspective

Bowlby's (1978) Attachment Theory states that "a stable, responsive, nurturing primary relationship enables the child to regulate his or her emotions and develop a secure base from which to explore, learn and form relationships with others." Additionally, WHO and UNICEF express "the importance of caregiver-child interactions for the survival and healthy development of young children" (Richter, 2004). According to studies in developmental psychology and child psychiatry, secure attachment to a primary caregiver is associated with healthy emotional and cognitive functioning in later life (Boris et al., 2000) (WHO & UNICEF, 2012).

The AAP emphasizes the importance of understanding families as dynamic entities that can have different configurations. For instance, they may have several or a few members. Parents or caregivers can be considered any and all individuals involved in the care of a minor. This may include opposite-sex, same-sex couples, or single parents as well as grandparents, aunts/uncles and foster parents. Families can be multiracial with only one child or several children. "Although it has predictable patterns, the family reshapes its daily life and support systems with the birth of each child in a way that fits with its unique mix of strengths and challenges" (American Academy of Pediatrics, 2017).

Miller, Gardiner, & Harding affirm that behavioural and emotional problems are a recurrent concern for parents of children with NDD/D. In their study, the findings highlighted commonalities that helped to build a categorization based on "functional attributes" rather than by specific diagnosis. This is the outcome:

Table 1: Parents/caregivers-reported behavioural and emotional concerns, (A. R. Miller, Gardiner, & Harding, 2018)	
Behavioural and Emotional Concern Clusters	**Behavioural and Emotional Concern Groupings**
Social Behaviours	• Social Isolation/Peer Engagement • Social and Interpersonal Boundaries • Picking Up on Social Cues and Conventions • Perspective Taking and Emotion Recognition • Problems with Play/Playing with other children • Social Communication • Social Problems • Avoids/Ignores other Children • Unrealistic Expectations of Friendship • Discriminating Between Friends and Strangers
Inflexibility/Gets Stuck or Fixated	• Rigidity, Need for Sameness, and Routines • Wants Things Own Way • Difficulty with Transitions • Compulsive and Ritualistic • Picky eating • Shifting Attention/Redirection Difficulty • Fixations and Obsessions
Tantrums/Outbursts/Meltdowns	• Tantrums/Outbursts/Meltdowns • Volatility/Self-regulation Difficulties • Dysregulated in Stimulating Environments
Attention/Concentration/Distractibility/Focusing	• Attention/Concentration/Distractibility/Focusing
Poor Task Completion and Follow Through with Routines (not due to defiance)	• Listening Difficulties • Difficulty Completing Tasks and Routines • Following Directions/Instructions • Disorganized
Sensory Issues	• Sensory Issues

Table 1: Parents/caregivers-reported behavioural and emotional concerns, (A. R. Miller, Gardiner, & Harding, 2018)	
Behavioural and Emotional Concern Clusters	**Behavioural and Emotional Concern Groupings**
Noncompliance	• Refusal/Defiance/Oppositionality • Disruptive
Odd/Unusual Behaviours	• Repetitive and/or Perseverative Speech, Movements, Noises, or • Other Behaviours • Odd/Unusual Behaviours
Hyperactive/Fidgety	• Hyperactive/Fidgety
Impulsive	• Impulsive
Anxious/Worried/Fearful	• Anxious/Fearful—Nonspecific • Anxious—Performance and Abilities • Anxious—Social Situations • Anxious—Being Alone/Separating • Specific Phobias/Fears • School-Related Anxiety
Odd Speech Behaviours	• Odd Speech Behaviours
Aggressive/Destructive	• Aggressive/Destructive • Self-Injurious Behaviours
Shy/Timid/Withdrawn	• Shy/Timid/Lacks Confidence • Hiding
Safety Awareness	• Safety Awareness

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Ritzema, Lach, Rosenbaum, & Nicholas state that the indices of poor mental and physical health are predominant in parents/caregivers of children with NDD/D because of their caregiving demands. Some of the main factors that cause concerns about their children are related to cognitive and communication, activities of daily living, behaviour/emotions, and body functions (Ritzema, Lach, Rosenbaum, & Nicholas, 2016).

Understanding Health Care Environments and the Health Professionals Role

The WHO points out that the environment is an important factor in children's development. It constitutes "the physical, social and attitudinal environment in which people live and conduct their lives." In the case of children and youth, their environment shifts continuously across the different stages of growth and age. For instance, infants and young children develop primarily in an "immediate environment". However, as they enter adolescence, their environment expands to "community and society" (WHO, 2007).

For children with special needs, their immediate environment will constitute their home and health care centres where they receive treatment. In Ontario, Children's Treatment Centres (CTCs) are the specialized establishments that serve children and youth with special needs and their families. According to a survey held on 2015-2016 by Empowered Kids Ontario (EKO), CTCs assisted over 74,355 children and youth: 51% corresponded to 0-4 years old, 42% ranged from 5-14 years old, and 7% represented 15-19 years old. The services offered at CTCs are organized based on community needs. A recent report determined that the most demanded services were: Speech-Language Therapy, Occupational Therapy, Physiotherapy, Social Work, Therapeutic Recreation, Audiology, Psychology, and Rehab Engineering (EKO, 2019).

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According to recent statistics, disability affects about 5% of Canadian children, where 74% of these children may have a neurodevelopmental disorder/disability (NDD/D). This fact also asserted that children with NDD/D require consistent access to health care services, especially paediatric and specialist visits (A. R. Miller et al., 2017). For instance, Grandview Children's Centre (Grandview Kids), a CTC that serves the Durham Region, received over 65,000 children, youth, and family visits throughout 2017/18.

As the population of children with NDD/D is growing, they are in the midst of an expanding process to address the increased demand for services (Grandview Kids Functional Program, 2018).

The role of health professionals is key to the development of children and their families. Building a partnership between parents/caregivers and health professionals opens a communication channel that promotes trust and freedom to ask questions and seek advice throughout the child's journey. Although health professionals' involvement is on an as-needed basis, parents/caregivers rely on their support to overcome challenges and support their well-being. Therefore, the importance of "family-centered care" that understands their cultural beliefs, and traditions, looks for each member's well-being, assesses and addresses risks, promotes clear communication, and provides information, resources, and services in a timely manner (American Academy of Pediatrics, 2017).

Understanding Transitions

Transition

Process of movement/shift

A

Environment

Change

Challenges

Opportunities

Stressful

B
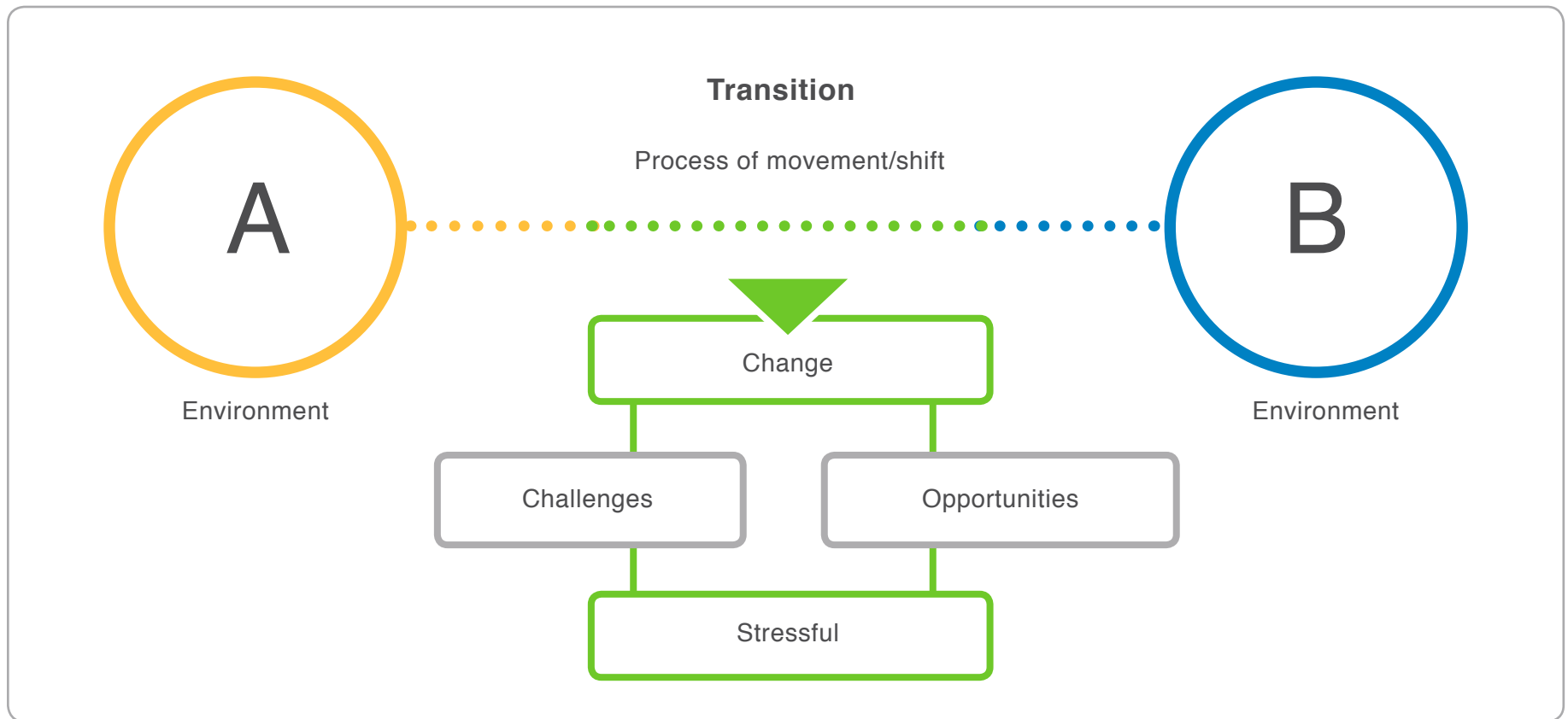
Environment

Figure 2. Transition process definition, (Rous, Teeters Myers, & Buras Stricklin, 2007)

Rous, Teeters Myers, & Buras Stricklin defined transitions as "a process of movement or shift from one environment to another and are an important part of human life, from infancy through adulthood. This movement or shift requires change, brings new opportunities and challenges, and often is regarded as stressful" (Rous, Teeters Myers, & Buras Stricklin, 2007).

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Understanding Transitional Spaces

According to Winnicott, transitional space implies "the space between the inside and the outside, the person and his environment. This is the space for creative symbol-formation because it is the function of symbols to connect and unite opposites" (Winnicott, 1971). For children, this space is hospitable, engaging, and encourages play. For instance, children can "quietly do their own thing, while knowing that the trustworthy, responsive mother is somewhere near and available if necessary. In this space the child can play safely, trusting his creativity, the usability of objects for symbolic play and the durable dependability of the mother, even if she must leave for short periods of time" (Grolnik et al., 1988).

Play as a Transitional Space

According to Winnicott, "play is part of the transitional phenomena. Playing becomes the link, the transition between two worlds: inside and outside, between psychic reality and external reality, between daily life and its caesuras. Thus playing is not entirely reality, it is true, but nor is it completely alien to it." Also he states that "play will have a form with a beginning, a middle, and a natural end" (Grolnik et al., 1988).

Additionally Bogajewski affirms that "if we see play as a free and serious activity subject to the pleasure principle, which takes place in a potential space in connection with transitional phenomena, structured by spatio-temporal limits and rules, capable of being understood at a non-literal and figurative level, then it seems possible to envisage infinite uses of it" (Bogajewski, 2018).

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Understanding Transitional Objects

In Winnicott's view, a transitional object represents an object chosen by the child that has a soothing and comforting function to help lessen the stress of separation from the child's mother or primary caretaker. The transitional object is a possession and not an internal object (a mental concept). The specifics of the relationship with the transitional object are shaped by the child's imagination in the context of their psychological needs and physical environment (Winnicott, 1971). Similarly, Grolnick (1990) states that a transitional object serves as a "prosthesis for memory" that enables the child "to hold" on to the mother a little longer in her absence. "Children usually choose transitional objects which are soft and can be cuddled, thus capable of eliciting a sense of being held, comforted, fed and played with. What is chosen is typically involved in the play and part of a progressive developmental process that involves interpersonal interaction" (Borenstein, 2019).

The purpose of transitional objects is to become a measure of defense against anxiety for children while they are apart from their mothers or primary caregivers. It is a resource that assists children to move from states of absolute dependence to relative dependence on them. Winnicott assets that "the object represents the ideal caregiver, who is omnipresent and always accessible. It must survive love, hate and pure aggression. It is the symbol of a journey, it seems really to be a two-way journey: both to the finding of the objective reality of the object and to the finding of the objective reality of the subject – the I AM" (Grolnik et al., 1988).

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Winnicott affirms that a transitional object can evolve from a child's thumb or fist to a piece of soft material found near the crib, to a softer stuffed animal, and finally to a toy. Good transitional objects can enlarge the child's real-world perception and become a companion that they can trust and hold while entering new spaces. Frequently, new environments can become frightening, especially for children. Therefore, carrying a faithful transitional object can help them to build a bridge between the known with the unknown and develop a sense of familiarity (Grolnik et al., 1988).

Winston clarifies that a transitional object is neither a distractor nor a soother, it aims to serve as an assistant that supports children. He also states that transitional objects can transform their original intent when children start to adapt to reality. The transitional object is diffused and spread over the entire intermediate area or cultural experience (e.g., culture, science, religion, feeding, dreaming, art), which has its origin with creative living and is manifested through play and transitional object formation, is a normal extension of the transitional process (Grolnik et al., 1988).

According to Sugarman, toddlers require a transitional object that not only connects with their senses (olfactory and tactile), but also their cognitive functioning. Therefore, they require a concrete, tangible object (Sugarman, 2017).

Cottis reflected upon the influence of transitional objects in children with learning disabilities and the value of acknowledging their significance, especially from people that are closer to them (parents/caregivers, health professionals) (Cottis, 2017).

She mentions the importance of empathy from health professionals towards children by recognizing the support that the transitional object provides to the children's life. Finally, she builds upon the "intrinsic creativity and 'self-building' potential" forged by playing and the influence in the therapeutic process itself. As she describes: "two unconscious minds can be at play together, interacting, and not constrained by working towards fixed outcomes. A range of materials such as sand, paint, water, and clay, along with various objects and toys, can be used by a therapist who is at all times in touch with their creative self, attuned to the child and supporting the child in developing and directing their ideas" (Cottis, 2017).

Stress and Anxiety

According to the United Nations International Children's Emergency Fund (UNICEF), stress can affect brain architecture during the early years. Children with NDD/D experience stress not only because of impairments but also for factors encountered in the immediate and external environments. The lack of stress management can lead to an increased risk of "stress-related physical and mental illness throughout childhood and the adult years." In the case of parents/caregivers of children with NDD/D, stress increases due to parenting responsibilities (WHO & UNICEF, 2012). Several studies agreed on the need of appropriate support for parents/caregivers and families to help alleviate the burden of daily care, childhood behaviour problems, cope with stress and increase parenting efficacy (Han, Yang, & Hong, 2018).

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Understanding Experience

In *Space and Place: The Perspective of Experience*, Tuan states that "experience is a cover-all term for the various modes through which a person knows and constructs reality. These modes range from the more direct and passive senses of smell, taste and touch, to active visual perception and the indirect mode of symbolization" (Tuan, 2008).

As Yi-Fu Tuan explains, experiences are constituted of emotions and thoughts. Although there is the common belief that one is opposed to the other (subjective vs. reality), both are ways of knowing. He also mentioned the importance of senses, as they are promoters of knowledge. For instance, sight and touch are the principal enablers of experiences within spaces. Additionally, he states that the world is a "spatial structure" built with spaces and places. A place is an object in which individuals can live and is a compound of geometrical characteristics. It becomes a reality when an individual can experience it through the senses and the mind. Knowledge influences the individual's feeling for places. On the other hand, space is defined by the ability to move. An individual learns about space through recognition of significant objects within the space (Tuan, 2008).

Children conceive places as large objects impossible to mobilize, and that can trigger different feelings. However, since the day they are born, their mother becomes the primary place, as she offers nurturing and comfort. Children are curious, and as they grow up their interest in exploring their surroundings increases. For instance, things, events, and people can trigger their attention. However, they will keep close to their mother, especially if the environment is hostile. Places become more specific as children grow. For instance, children understand the meaning of where and acquire a sense of place and security at two years old. Later on, they can recognize landmarks, read spatial and environmental cues such as pictograms or signage, and can associate people with specific places. Experience, for children, "is an active search and occasionally wild extrapolations beyond the given" (Tuan, 2008).

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Play as an Experience

Play is dynamic in nature and is an important tool for the development of human learning and creativity. According to Winnicott, playing is always a creative experience in the space-time continuum and is considered a basic form of living (Grolnik et al., 1988).

The UNICEF recognizes play as children's right and its primary occupation (UNICEF, 1989). Play is defined as an activity in which children experience freedom, choice, and control (Sheridan et al., 2011). Play opens children's understanding of their surroundings and encourages learning about spatial relations through imagination. From the occupational therapy researchers perspective, "play experience is a combination of internal control, intrinsic motivation, and freedom from reality. These components of play are found within a "frame"--the frame being the nonverbal cues, such as facial expression, that indicate to someone else that a child is playing (Bundy, 2012).

Variables such as gender and age can be factors that influence children's play. For instance, parents/caregivers' usage of stereotype toys and labeling may contribute to gender differences. Similarly, children's development influences the choices and ways in which children play (Miller & Kuhaneck, 2008). In the case of children with disabilities, the experience of play is perceived as limited. However, studies have found that children with disabilities experience play differently. "They can have attention drawn both toward and away from their disability in play, and the need for a helper can be experienced as normal" (Graham, Nye, Mandy, Clarke, & Morriss-Roberts, 2018). Children perceive the experience of play as opportunities to be independent, able to make choices, have a sense of identity and belonging, and have fun.

CHAPTER 3: METHODOLOGY

The objective of this study is to develop a prototype of a transitional support system that helps children with NDD/D to minimize the behavioural/emotional challenges generated by transitions when visiting a treatment centre. Through qualitative ethnographic and quantitative research methods, this study focused on understanding their unique abilities, behaviours/emotions, and experiences when visiting a treatment centre and the role of parents/caregivers and health professionals as facilitators of experiences and medical care.

Considering that the input from living human participants and vulnerable populations were required, the methodology and methods used in this study were approved and conducted as per the OCAD University and Grandview Kids Research Ethics Board (REB No. 2019-36).

A consent form that outlined a summary of the study, the specific research method to be performed, the length of time required, and an acknowledgment of participants' confidentiality was given in print to each participant for review. In the case of underage participants, an assent form was developed that showcased a similar content as the consent form, but in a simpler language. Finally, to recruit participants we relied on Grandview Kids' support, as they kindly displayed the announcements on their website and Facebook channel. Also, personal networking helped to recruit more interested participants.

Primary and secondary data was collected through an incremental model that resulted in three stages: observation, semi-structured interviews along with literature review, and co-design sessions.

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First Stage - Observation

Observation helped to understand children' with NDD/D behaviours/emotions while transitioning into the children's treatment centre, and identified the role of parents/caregivers as facilitators of experiences for children. These observations were conducted at five children's treatment centres in different areas of the province. These environments offered specialized programs and support to children with special needs and their families. The locations selected for observation were: Grandview Kids (Oshawa), Ron Joyce Children's Health Centre (Hamilton), Holland Bloorview Kids Rehabilitation Hospital (Toronto), Surrey Place (Toronto), and The Hospital For Sick Children (Toronto). Each observation lasted approximately 2-3 hours and was held at different times of the day. For instance, 3 locations were visited from 8:00 a.m. to 10:30 a.m. and 2 locations from 4:30 p.m. to 6:30 p.m. Data was recorded by note-taking and transcribed into a Microsoft Excel spreadsheet. See Appendix A.

Second Stage - Literature Review & Semi-structured Interviews

A literature review helped to find evidence-based resources published in academic journals, conference publications, government databases, books, and recognized healthcare organizations such as WHO, UNICEF, AAP that promoted the understanding of children's development, neurodevelopmental disorders and disabilities, parents/caregivers' perspectives, children's treatment centres, and health professionals' role. Additionally, the literature review highlighted the issues that children encountered in relation with transitions. The findings guided the construction of questions for the semi-structured interviews, co-design sessions, and consequently the prototype design.

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METHODOLOGY

Semi-structured interviews were conducted to gain better insight into children with NDD/D's journey when visiting a treatment centre, and the role of parents/caregivers and health professionals in this process. Eleven participants were interviewed.

Three participants were users of the children's treatment centre, seven worked or volunteered at a children's treatment centre, and one worked at a regulatory organization for children's treatment centres. The semi-structured interviews had a duration of 60 minutes. These were held in-person, by videoconference or phone-calls depending on the participants' preference and availability. Data was collected by audio/video recordings and note-taking. Each interview was transcribed using NVIVO and subsequently coded. See Appendix B & C.

Third Stage - Co-design Sessions

A co-design session was conducted to consolidate the findings obtained through the previous stages. Eight health professionals such as occupational therapists, physiotherapists, social workers, and speech-language pathologists who worked with children with NDD/D attended the session. It was held at a meeting room in the Grandview Kids facility located in Ajax and lasted for approximately 60 minutes. The objective of the session was to trace a child's journey when visiting the children's treatment centre and identify challenging transitions. Participants were given a persona profile, for example, – Peter a 5-year-old boy with a mild developmental disability who was attending a treatment session (Figure 3). In order to diagram this process, participants were provided with blocks of paper cut in different shapes, and with alternated colours to graphically frame the start, middle, and end of Peter's journey (Figures 4,5,6) Data was collected by photos and audio/video recordings.
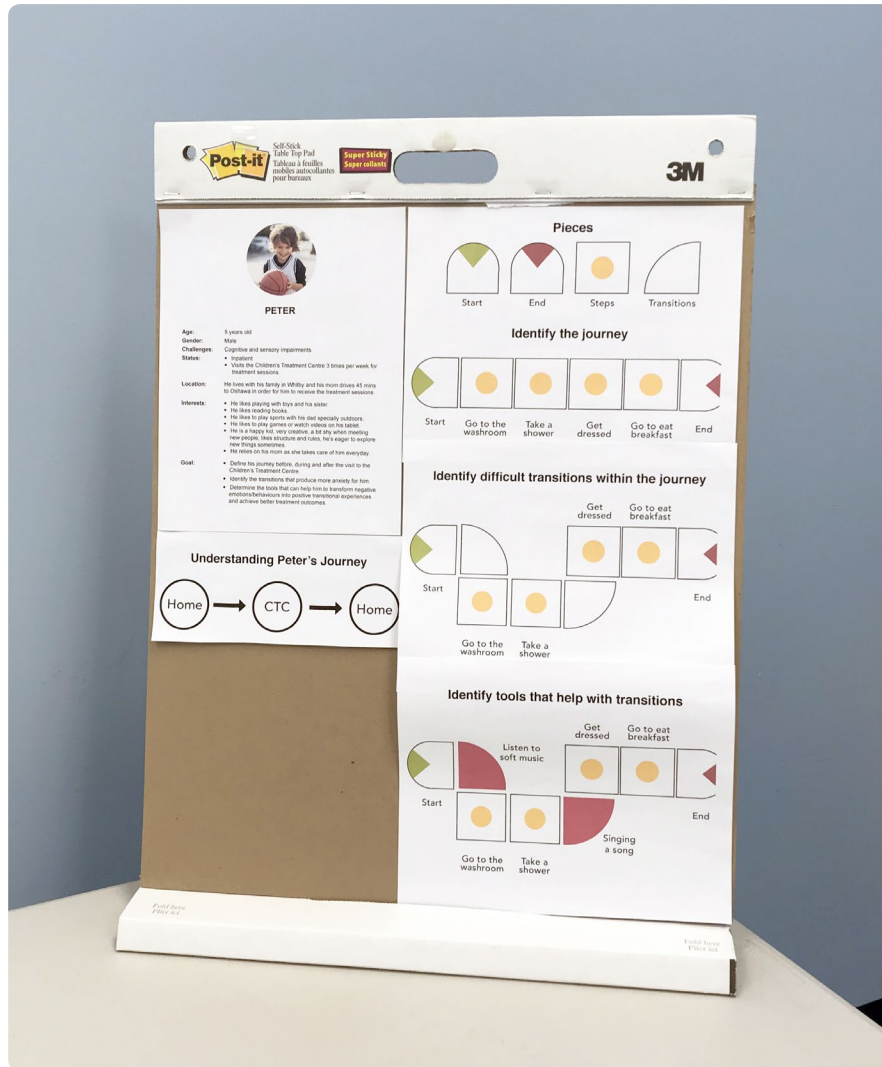
Figure 3. Persona profile and visual instructions for the co-design session
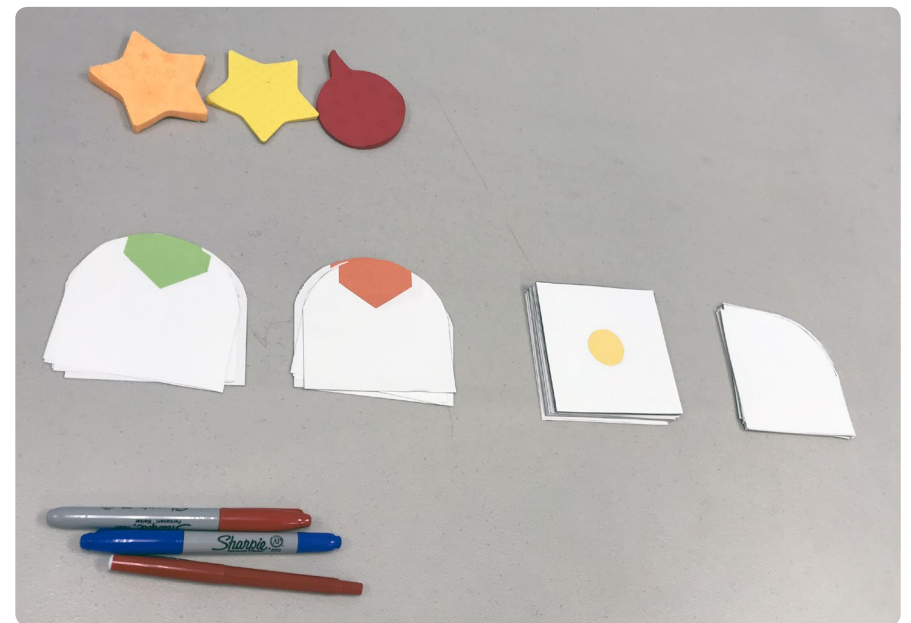
Figure 4. Materials provided to design the child's journey
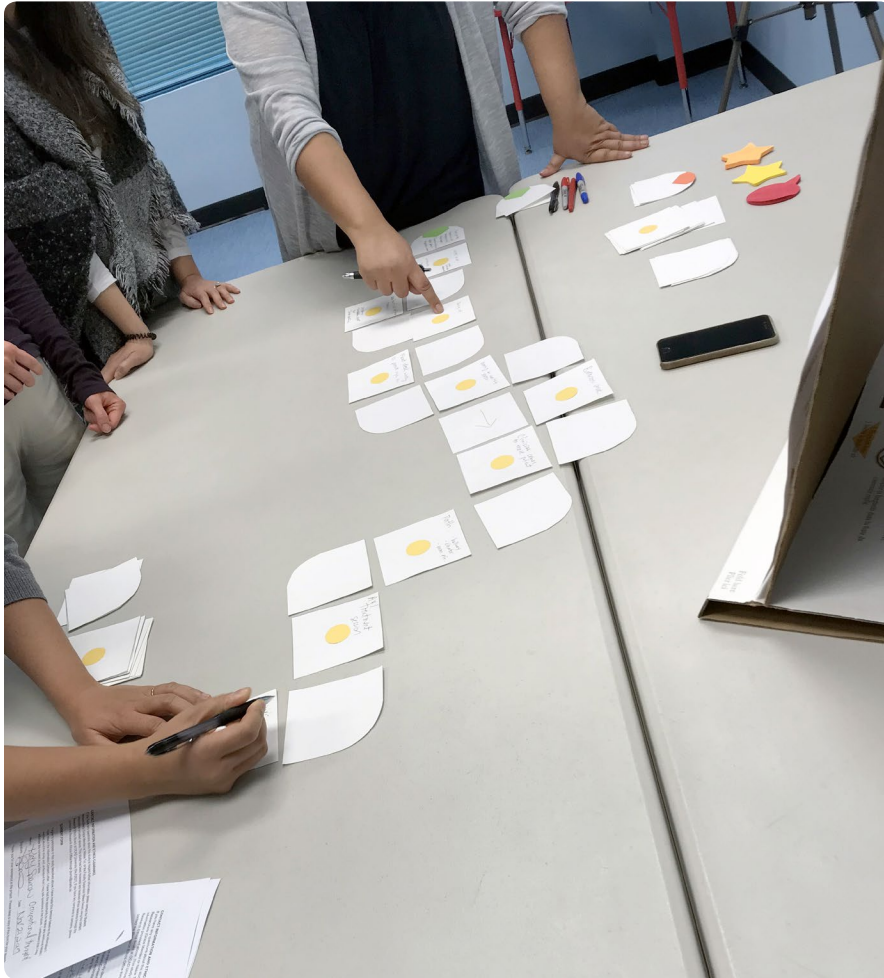
Figure 5. Participants designing the child's journey

Figure 6. Co-design session final outcome

CHAPTER 4: DATA ANALYSIS

In this study, observations helped to determine if there was a correlation between transitions and children with NDD/D's challenging behaviours/emotions. The data were analyzed through a descriptive approach that identified children with NDD/D's demographics, behaviours/emotions, and transitions through the environment. As a result, children from 1 to 10 years old and their parents/caregivers were the populations that most frequently visited the treatment centres. In regards to their behaviour/emotions, most children tended to be shy, stressed, not communicative, while others denoted being upset, crying, and with physical discomfort. Similarly, parents/caregivers' behaviours were attentive, cautious, eager to help, and incentive communication. However, in other instances, they were tense, apologetic, and stressed by trying to diminish the challenging behaviours/emotions of their children. Finally, three main transitions triggered challenging behaviours/emotions in children with NDD/D: when entering the facility, going into and out of the treatment session, and exiting the facility.

These findings aligned with EKO's Key Performance Indicators (2015 – 2016) that enounced that 93% of children's treatment centres' clients corresponded to children between the ages of 1 to 14 years old and their parents/caregivers (EKO, 2018). Through observation, this study understood that when visiting a children's treatment centre, children tended to follow their parents/caregivers' lead. Therefore, children's perception of the environment is influenced by their parents/caregivers' input and they are not necessarily engaged with the space.

Similarly, children with NDD/D and their parents/caregivers relied on the health professionals' support and knowledge when visiting a children's treatment centre. Children with NDD/D might require varied services across different locations. According to EKO's survey findings, the services more used at children's treatment centres were speech-language therapy, occupational therapy, physiotherapy, social work, therapeutic recreation, audiology, psychology, and rehab engineering (EKO, 2018).

The data gathered at this first stage helped to design a conceptual map (Figure 7) that identified the levels of interactions between children with NDD/D, parents/caregivers and health professionals, and distinguished primary and secondary environments and its influence in children with NDD/D development.
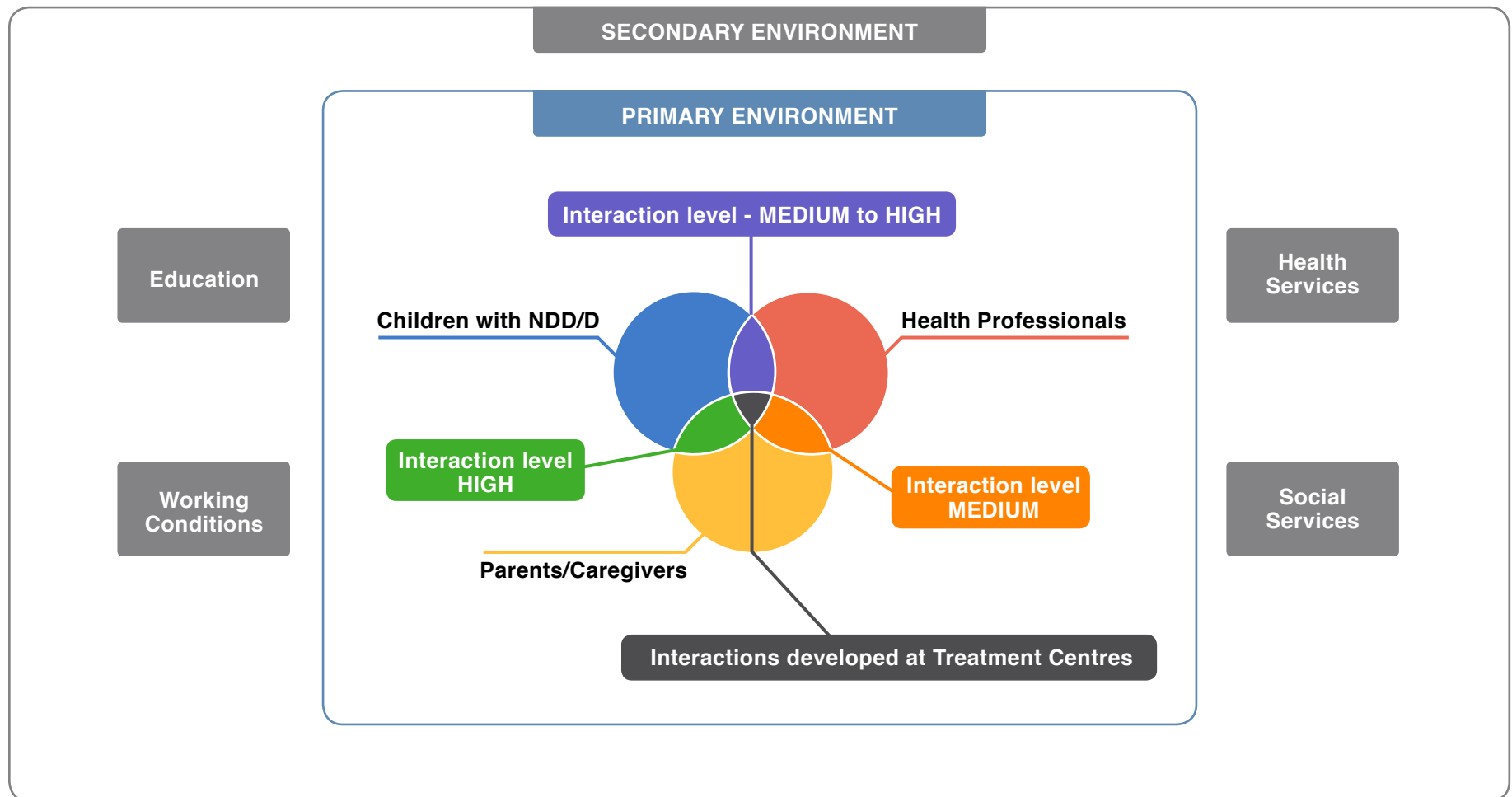
Figure 7. Model of interactions developed at treatment centres
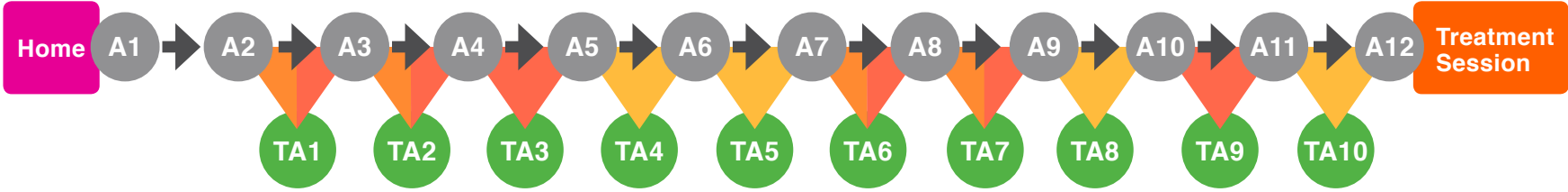
Subsequently, the objective was to have a better understanding of children with NDD/D, parents/caregivers, and health professionals' lived experiences and perspectives about children's treatment centres environments. The data collected through semi-structured interviews were analyzed and coded based on a thematic approach that defined a framework of Basic, Organizing, and Global Themes (Attride-Stirling, 2001). As a result of this inductive process, we clustered the data into five themes: provide structure, minimize challenging behaviours and emotions, develop motivating activities, embrace diversity and inclusion, and support the integration into real life. These constructs would become the potential components of the Transitional Support System illustrated in Figure 8.

BASIC THEMES	ORGANIZING THEMES	GLOBAL THEMES
We have defined routines. Breaking tasks into specific steps	Defined routines, tasks and steps	**Provide structure**
Children are good at following directions and specific steps	Follow directions and specific steps	
Children likes consistency. Things working and where they belong	Like consistency	
Any interruption in routines causes anxiety and stress	Interruptions causes stress	**Minimize challenging behaviours/emotions**
Not knowing what will happen causes emotional discomfort	Uncertainty triggers negative behaviours	
Any change in their pattern lead to some disruptive behaviours	Changes trigger disruptive behaviours	
Children require strong motivators if you want them to try new things	Require motivation	**Develop motivating activities**
You tried something new and it was a lot of fun	Have fun	
If a kid is motivated by an activity they will be attentive to it	Motivated and attentive	
Consider users with wheelchairs	Functionality	**Embrace diversity and inclusion**
Family's background influences children's behaviours and emotions	Family background	
Games should have active and sedentary pieces	Multiple abilities	
I think we're always trying to prepare children for the real world	Prepare for the real world	**Support integration into real life**
We have to start making integration into life a priority	Integration into real life	
Make sure that they can function within the areas that they want to function	Independence	

Figure 8. Cluster of basic, organizing and global themes, Thematic Network analysis, (Attride-Stirling, 2001)

Finally, a detailed understanding of the steps taken by children with NDD/D and their parents/caregivers when visiting the children's treatment centre helped to identify challenging transitions and their impact level throughout their journey. The participants in the co-design session identified two phases. Phase A comprised starting at home and arriving at the treatment session. There were ten transitions identified that caused challenging effects in children with NDD/D. Most of them were considered moderate to severe (Figure 10). Phase B involved the start point when children left the treatment session and ended when they arrived home. Seven transitions were recognized and indicated a low to moderate intensity (Figure 11). These findings would guide the development of tools for the Transitional Support System.

Table 2: Phase A: Home to Treatment Session, steps and transitions developed in children's with NDD/D journey

Steps	Activity	Transitional Impact		
		Low	**Moderate**	**Severe**
A1	Parent/caregiver provides Grandview with background info + book appointment			
A2	Parent/caregiver Mental Preparation - What to expect, how to prepare the child Child Mental Preparation - Announce we are going to Grandview			
TA1	Transition		**X**	**X**
A3	Out of the house routine - Dressing, transitional object, car, routine			
TA2	Transition		**X**	**X**
A4	Arrive to parking lot			

Steps	Activity	Transitional Impact		
		Low	Moderate	Severe
Table 2: Phase A: Home to Treatment Session, steps and transitions developed in children's with NDD/D journey				
TA3	Transition			X
A5	Front Desk waiting as parents sign in			
TA4	Transition	X		
A6	Waiting in the waiting room / Bathroom Break			
TA5	Transition	X		
A7	Clinician comes to receive patient			
TA6	Transition		X	X
A8	Follow the path - Hallway, elevator, room			
TA7	Transition		X	X
A9	Getting into the treatment space			
TA8	Transition	X		
A10	Using treatment space for activities. They vary depending on SLP or OT and the environment elements (light, temperature, noise, furniture)			
TA9	Transition			X
A11	Next Activity or schedule next appointment. Sometimes this is waiting for the child while parent/caregiver and clinician talk			
TA10	Transition	X		
A12	Session is finished - Clinician tells family			

Table 3: Phase B: Treatment Session to Home, steps and transitions developed in children's with NDD/D journey
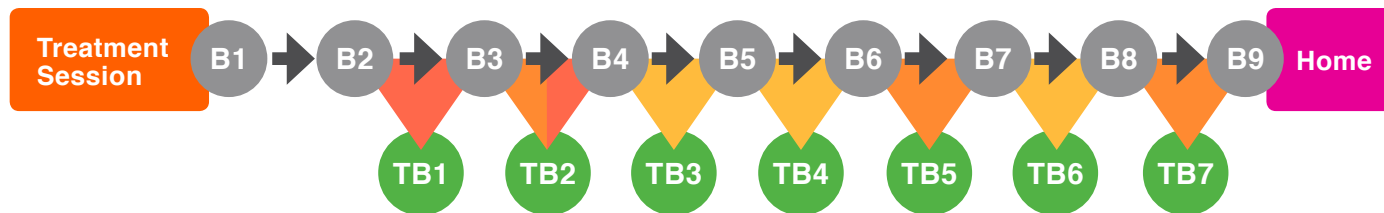
Steps	Activity	Transitional Impact		
		Low	Moderate	Severe
B1	Parent/caregiver tell / help child to leave			
B2	Child Mental Preparation: Verbal, behavioural, visual strategies, physical help			
TB1	Transition			X
B3	Leave the room			
TB2	Transition		X	X
B4	Follow the Path - hallway, elevator, room			
TB3	Transition	X		
B5	Pass the waiting room			
TB4	Transition	X		
B6	Pass front desk			
TB5	Transition		X	
B7	Exit to parking lot			
TB6	Transition	X		
B8	Enter the car			
TB7	Transition		X	
B9	Arrive home			

CHAPTER 5: CONCEPT DESIGN

For the design process, this study will rely on the findings acquired through the qualitative and quantitative research methods to develop a Transitional Support System that can support children with NDD/D to minimize the behavioural and emotional challenges presented by transitions when visiting a children's treatment centre.

The structure of the design will be based on five key elements: users, environments, phases of the visit, behavioural and emotional challenges presented due to transitions, and global themes.

1. Users:

Children with NDD/D   **Parents/caregivers**   **Health Professionals**
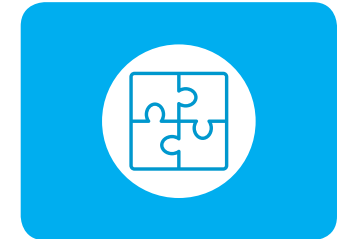
2. Environments:

Home

Car

Treatment Centre:
- Parking Lot
- Entrance/Exit
- Reception
- Waiting Room

Treatment Session

3. Phases of the visit:

Phase A: Home to Treatment Session

Phase B: Treatment session to home

4. Behavioural/emotional challenges presented due to transitions:

Low   Moderate   Severe

5. Global Themes:

Provide structure:

Children with NDD/D need to have a clear path of actions to be taken before visiting an environment. They rely on routines and consistency as mechanisms to feel secure and comfortable. Additionally, having a structure helps them to focus on the activities to be performed and facilitate their learning.

Minimize challenging behaviours/emotions:

Uncertainty triggers challenging behaviours/emotions in children with NDD/D. By not having enough information (what, why, when, where, with whom) children felt overwhelmed and stressed. Therefore, the information provided in a timely and descriptive manner will help to promote emotional support, create positive associations, and allow children to feel secure and comfortable.

Develop motivating activities:

No matter their abilities, children always look forward to having fun, enjoy, and be engaged through different activities. Tools should be simple, easy to use and encourage creative play that promotes positive experiences.

Embrace diversity and inclusion:

Children are unique and diverse human beings. For this reason, the interest in developing tools that can reflect their identity and functionality, and that can be accessible for them and their families.

Support integration into real life:

Modify the perception of visiting a treatment centre as an obligation. Instead, promote the idea of an activity that will help children to become more functional, able to have fun by sharing and playing with others, and connecting with the community. Therefore, tools should help children to become independent and able to create positive associations with others and their surroundings.

Figure 9 represents the elements previously described within a general context to provide a deeper understanding of their role in regards to children with NDD/D's journey when visiting a treatment centre.
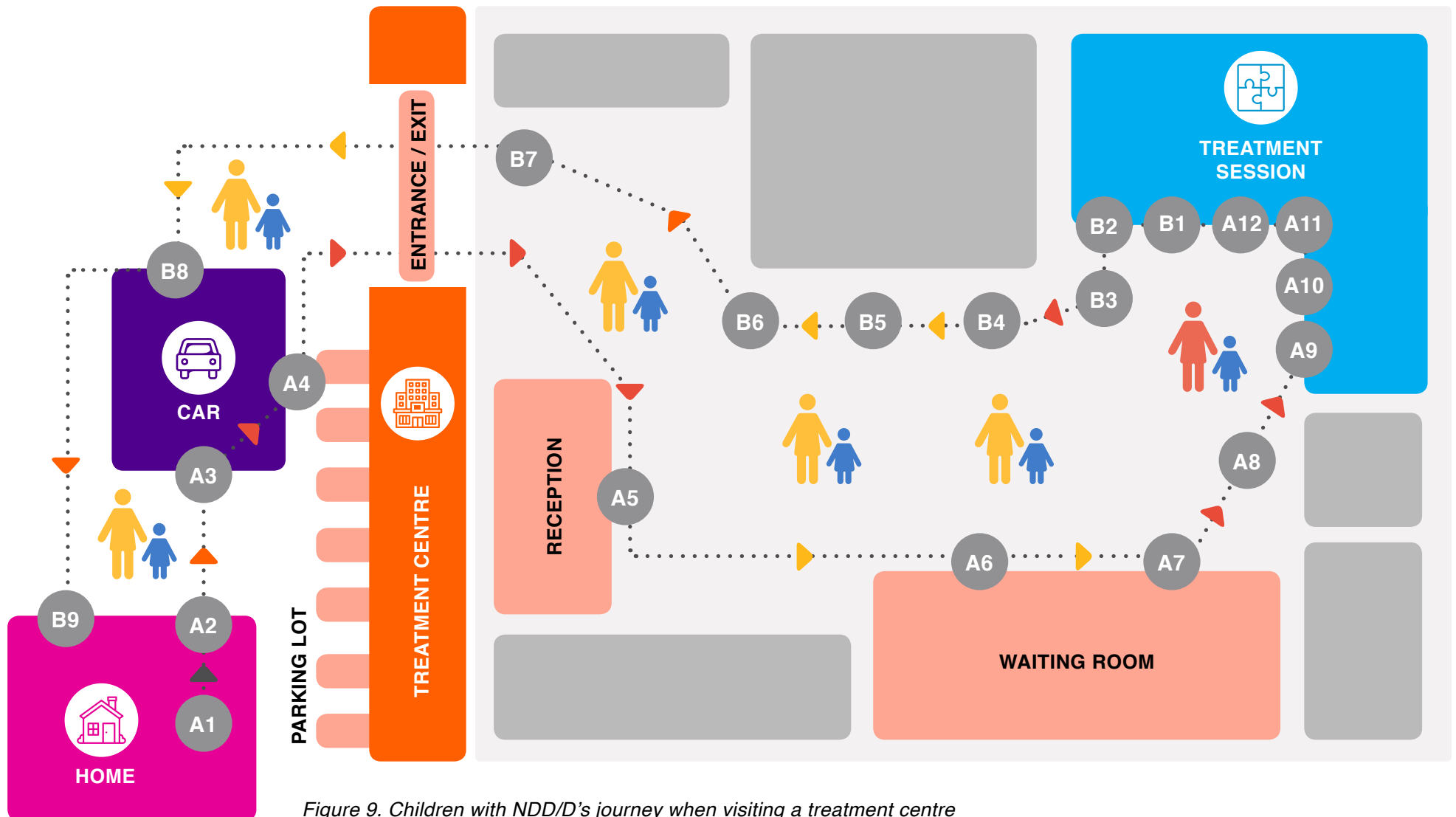
Figure 9. Children with NDD/D's journey when visiting a treatment centre

For the development of the Transitional Support System (TSS), we considered the behavioural/emotional challenges experimented by children with NDD/D at each phase (Figures 10 & 11) and presented possible solutions supported by findings through the research methods implemented in this study.
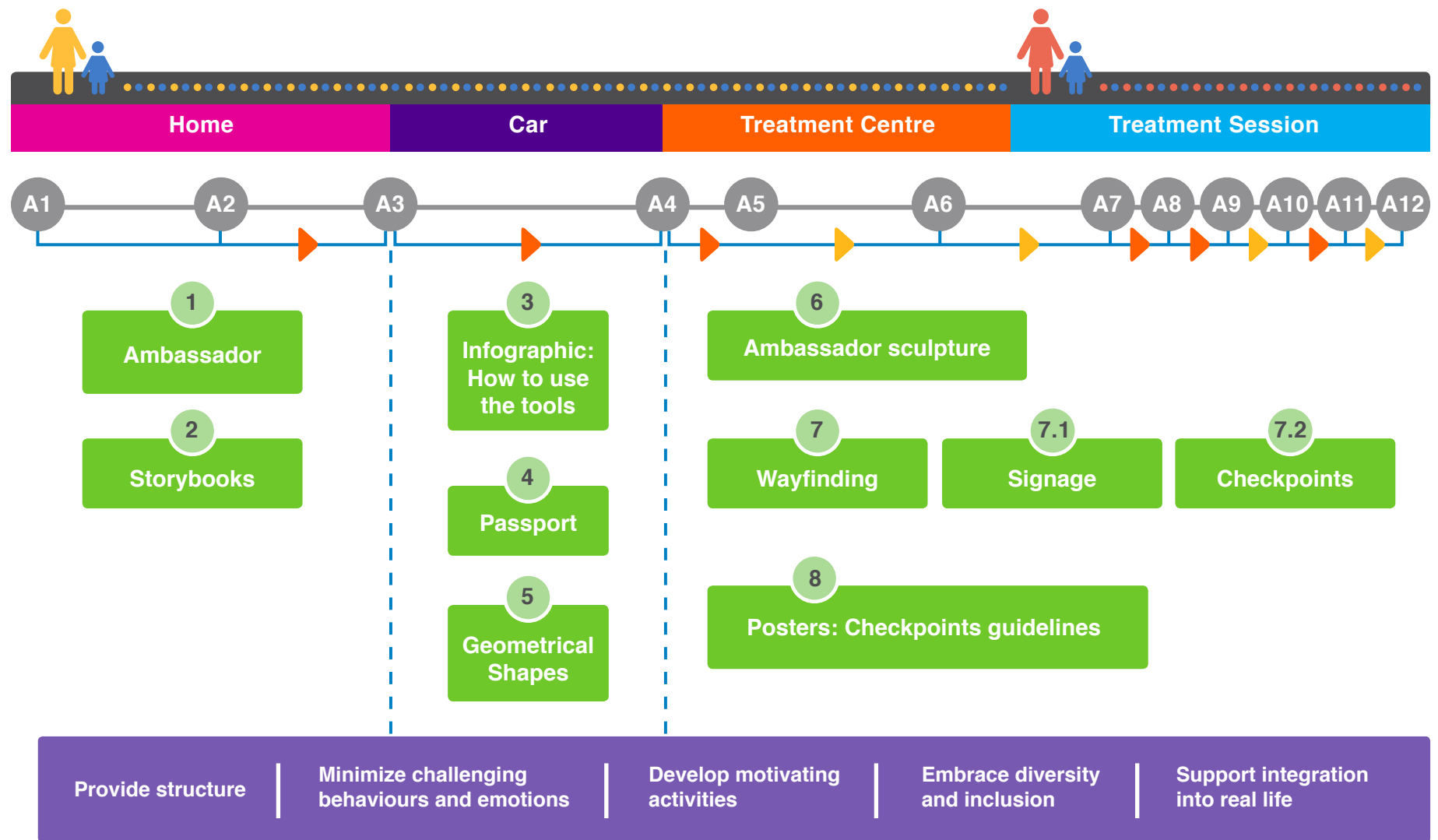
Figure 10. Phase A, overview of recommended tools for the transitional support system
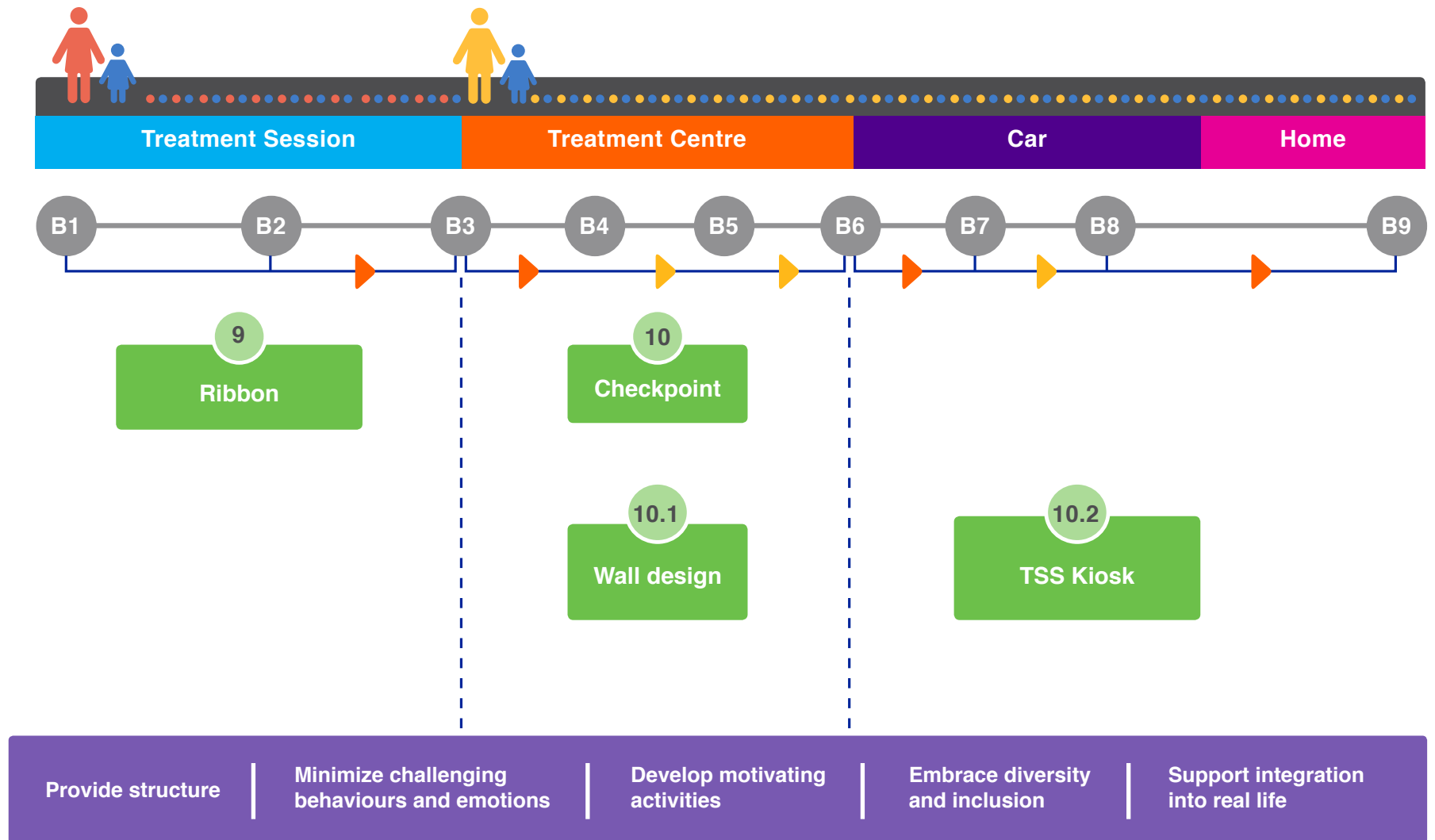
Figure 11. Phase B, overview of recommended tools for the transitional support system

CHAPTER 5:

CONCEPT DESIGN

Design Strategy: PHASE A - Recommended Tools

1 | **Ambassador**

This study took into consideration the importance of establishing a trustworthy relationship that positively influences and regulates children's behaviours and emotions. For instance, parents/caregivers provide children with support and care that enable them to feel secure and comfortable. Similarly, Bowlby's (1978) Attachment Theory denoted that having a stable and responsive primary relationship helped children to regulate their emotions and develop a secure base to explore, learn, and build relationships with others.

Based on these findings, we understood the need to create and introduce a recognizable figure that is friendly, fun, and whose story is relatable to children with NDD/D. Its role would be to become the ambassador of the children's treatment centre that is in charge of preparing, guiding, and supporting children with NDD/D through the process of visiting to the treatment centre. The aim is to develop an ambassador-child relationship that promotes trust, security and empathy.

When participants were inquired about things they liked, their interests highlighted the preference for animals. For instance, dogs, cats, rabbits were some of the preferred, but when asked to consider Canadian animals their favourite choice was beavers. Similarly, parents/caregivers highlighted the sense of belonging to this country and the support provided towards their children's well-being. Therefore, the intent to portray Logan, the Canadian beaver (Figure 12), as the ambassador of a children's treatment centre.
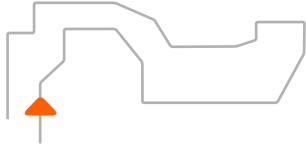
1

- Friendly

- Relatable

- Fun

LOGAN,
the Canadian
Beaver

Figure 12. Recommended ambassador design

CHAPTER 5:
CONCEPT DESIGN

2 **Storybooks**

According to studies on transitions, uncertainty and changes in routines were considered major triggers of challenging behaviours/emotions in children with NDD/D. When participants were asked about this topic, they confirmed the need to provide information in advance to prepare the child for the change and try to minimize the transitional challenges that it might bring. For instance, parents/caregivers tended to rely on *social stories* to explain information to their children specially when visiting new environments.

Based on these findings, we identified the necessity to provide information in advance to children with NND/D about what is a CTC, the purpose of the visit, the actions that would take place in the environment, the steps that they would need to follow, and the people that they would meet. Additionally, introduce the ambassador, its story, and role in the CTC.

In Sugarman's view, children require objects that are concrete and tangible to connect with their senses and cognitive functioning (Sugarman, 2017). Therefore, the idea to design storybooks with a simple narrative and descriptive imagery that inform and support children with NDD/D (Figures 13 & 14) to minimize the uncertainty when visiting a treatment centre.

2
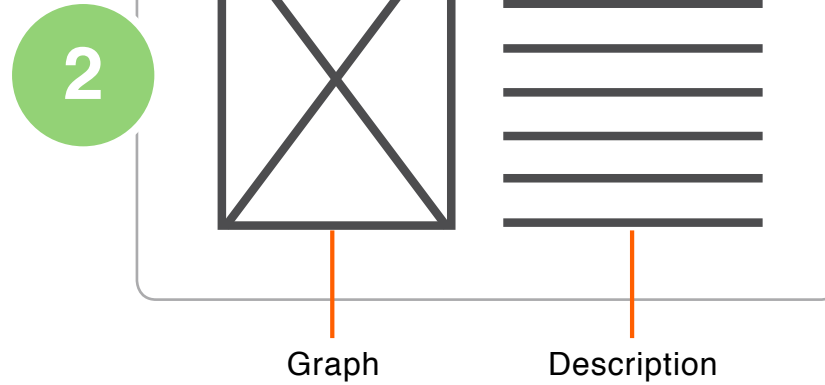
Figure 13. Recommended storybook framework

Graph   Description

2.1 **Let's Meet Logan the Ambassador**

Hi!

I am LOGAN, the Children's Treatment Centre Ambassador

2.2 **Let's Visit the Treatment Centre**

Photo by HamiltonHealthSciences.ca

Let's Visit the Children's Treatment Centre

Figure 14. Recommended storybooks design

CHAPTER 5:
CONCEPT DESIGN

3 Infographic

A topic often discussed by participants was the need for consistency. They acknowledged the need to keep changes to the minimal in order to avoid challenging behaviours/emotions in their children. If a change was required, they looked for resources that can help explain the reason for the change and highlighted the differences that would take place in order for the child to be prepared and minimize the transitional effect.

Similarly to storybooks, the infographic (Figure 15 & 16) aimed to prepare children with NDD/D for the activity that would take place once they arrive at the treatment centre. This tool would maintain a simple narrative and descriptive imagery in order to promote consistency. The recommended structure would consist of an introduction to the activity, a description of tools, and a guide of the steps to be taken.

3

Title

Ambassador

Description

Tools

Images &
Descriptions

Steps

Images

Description
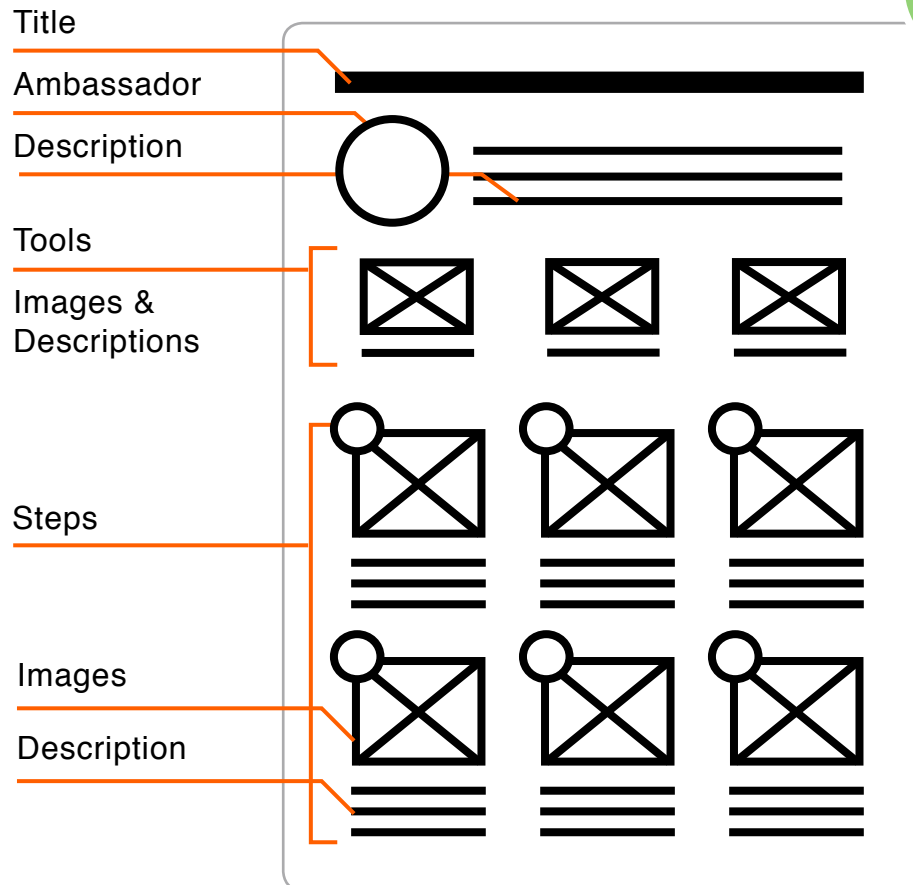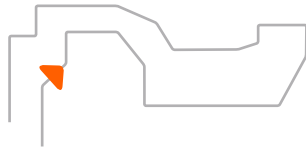
Figure 15. Recommended infographic framework

Let's Explore the Treatment Centre

Introduction to the activity

You'll need: ① ②

Steps:

①	②	③
Photo	Photo	Photo
Description	Description	Description

④	⑤	⑥
Photo	Photo	Photo
Description	Description	Description

HAVE FUN!

Figure 16. Recommended infographic design

CHAPTER 5:
CONCEPT DESIGN

4   **Passport**

According to UNICEF, play is children's primary occupation (UNICEF, 1989). Through play, children understand their surroundings, learn through imagination, experience freedom, choice, socialization, and creativity. Play is a right that children have no matter their abilities or functionality.

Play creates enriched and positive experiences for children. When they have fun, they want to repeat an activity. Based on participants' perspectives, children with NDD/D felt more comfortable and secure when they performed activities that they have done before. The passport (Figure 17 & 18) would support children with NDD/D by pre-visualizing the actions to take place once they enter the treatment centre. Children with NDD/D would feel less stressed by knowing what to expect, whom they would meet, and the different stages required to be reached in order to complete the visit to the treatment centre.
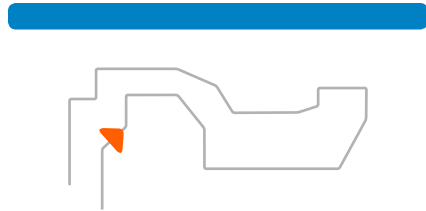
Action to be taken

Image of space

Ambassador

Brief description

Figure 17. Recommended passport framework

4

This passport belongs to:

Your Name:

Favourite Food:

Favourite Colour:

Favourite Sport:

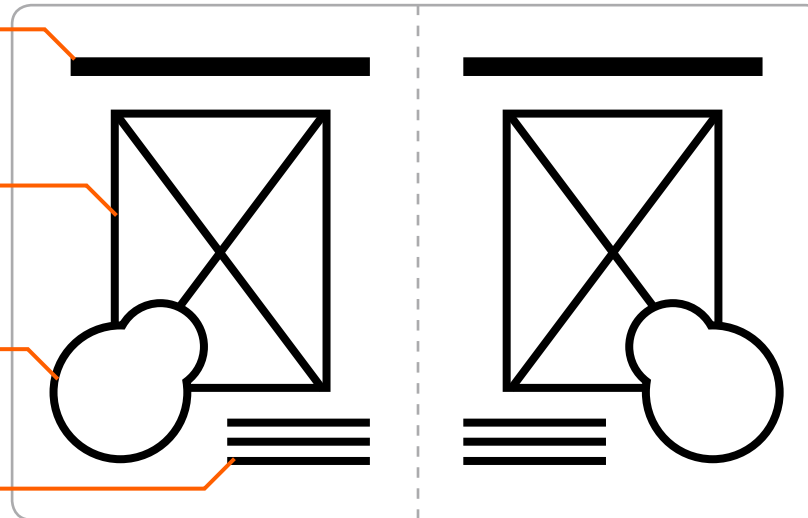**1** **Let's meet the receptionist!**

Photo by HamiltonHealthSciences.ca

The receptionist is a person that provides information to the people and guides users through the facility. Say Hello!

Figure 18. Recommended passport design

CHAPTER 5:
CONCEPT DESIGN

5 **Geometrical Shapes**

Tuan affirms that individuals experience places through their senses. Sight and touch are the principal enablers of experiences and knowledge. In the case of children, places are conceived as large objects compound of geometrical characteristics that can trigger different feelings. Places become more specific when children grow as they acquire a sense of place and security (Tuan, 2008).

Based on the participants' perspectives, children with NDD/D's attention were driven towards objects that offered sensorial input. Some of the objects specified were squishy toys, sensory tables, and textures. For instance, health professionals used tactile objects when children needed to calm down or to have a break to gain their focus to continue an activity.

The idea behind the design of geometrical shapes (Figure 19) was to provide children with NDD/D with textured, colourful, and three-dimensional objects that would complement the experience of navigating through the treatment centre. The design would take into consideration dimensions that are safe for children to use. Additionally, to define a structure that would provide children with NDD/D with the feeling of control while engaging their senses.

5

Front desk

Waiting Room

Treatment Room

- 3D
- Coloured
- Textured
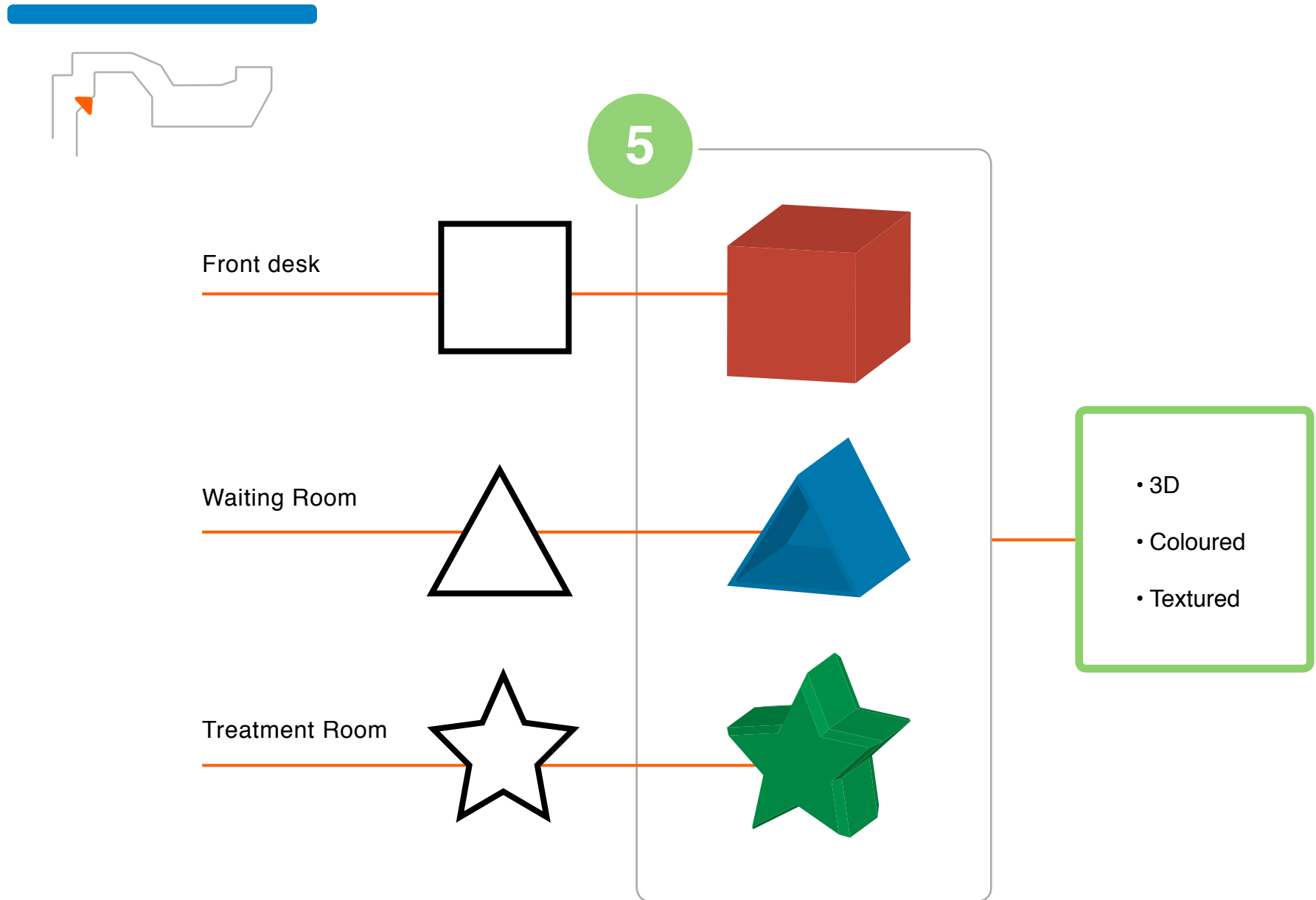
Figure 19. Recommended geometrical shapes design

CHAPTER 5:
CONCEPT DESIGN

6 **Ambassador sculpture**

Similar to the geometrical shapes, the sculpture (Figure 20) aimed to supply children with NDD/D with a tactile object that they would be able to interact with during the visit to the treatment centre. When participants were asked about the things they liked in the facility, one of the most recurrent answers was the sculptures that some treatment centres displayed along the different spaces. As a result, we would introduce a scaled version of the ambassador that would welcome children with NDD/D to the environment, engage their senses, help them to feel comfortable and safe, and reinforce its role as guide.
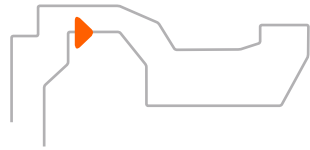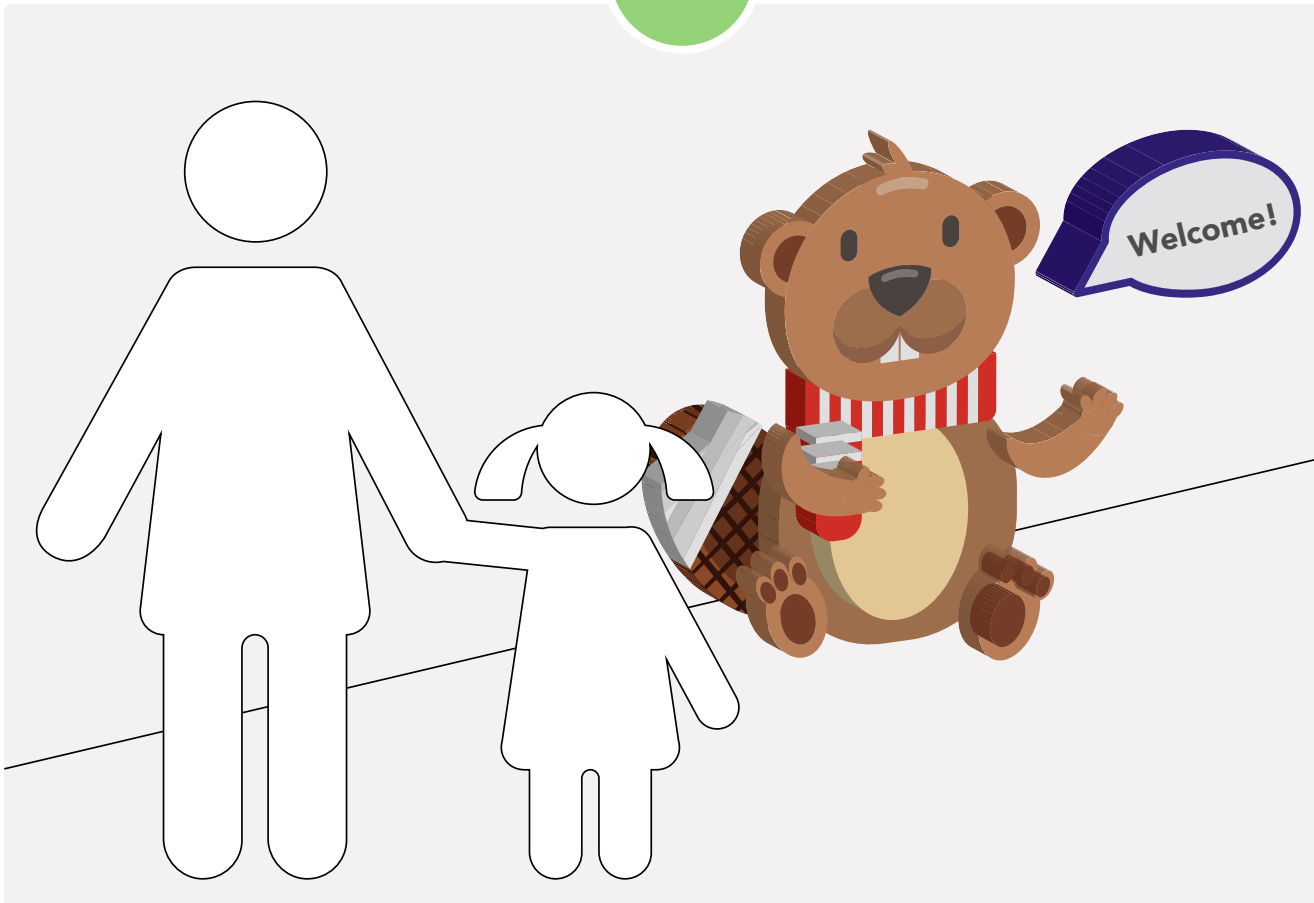
Figure 20. Recommended ambassador sculpture design

CHAPTER 5:
CONCEPT DESIGN

7

7.1

Wayfinding - Signage

Wayfinding is the process of designing cues to help people navigate a built environment. These clues can be signage, lighting, colour and even architecture. An effective wayfinding should consider connectivity, continuity, and consistency. Being able to see as much as possible from any vantage, is the most effective form of wayfinding (Zweig, 2014).

Based on participants' comments about their experiences when navigating a treatment centre, most respondents agreed that exploring space for the first time was always challenging, especially if it did not have clear signage. It took longer for them to find the right rooms and increased the stress on their children. The more familiar they were with space, the easier the navigation. They believed that having a clear path to follow once they arrive at the treatment centre would help to overcome uncertainty and minimize the challenging transitional effects.

To design an effective wayfinding system, we identified the path that children would take during the visit to the treatment centre and developed simple, colourful, consistent signage that would be easy to identify and visible from different distances. The main areas considered were: front desk, waiting room, treatment room, and exit. Each was assigned with a specific colour and geometrical shape to align with previous tools in order to create a consistent and clear navigation that would enhance children with NDD/D experience (Figure 21).

The proposed signage has focused on the graphic and orientation elements. However, considerations such as size, height, and materials would require an architectural scope.
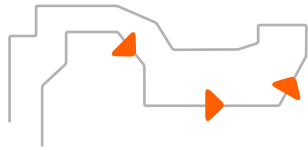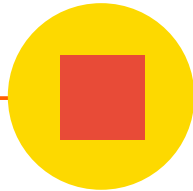
Front desk area

Waiting room area

Treatment room area

Exit area

7.1
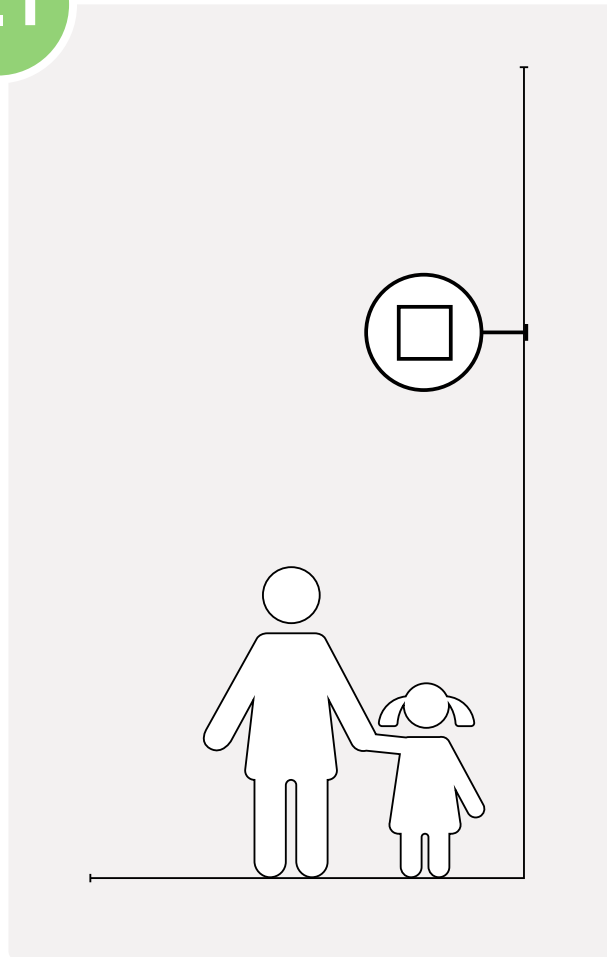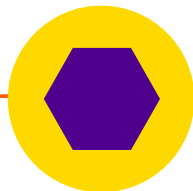
- 3D

- Coloured

- Visible at distance

Figure 21. Recommended signage for front desk, waiting room, treatment room, and exit areas.

CHAPTER 5:
CONCEPT DESIGN

7

7.2

Wayfinding - Checkpoints

As part of the wayfinding system, checkpoints (Figure 22) were designed to create entertainment for children with NDD/D while their parents/caregivers have to comply with requirements such as signing in at the front desk or virtual kiosk. Children with NDD/D would have to find a geometrical figure that corresponds to this specific area and proceed to place the object in the corresponding bin. Once that is completed, they would be able to move to the next stop.

As participants' suggested, children with NDD/D tended to feel frustrated when they had to wait while their parents/caregivers had to comply with procedures. By designing activities that involve their senses and creativity, children with NDD/D would be engaged, eager to participate, minimize challenging behaviours/emotions, and create positive experiences.

Similar to signage, the proposed checkpoints have focused on the graphic and orientation elements. However, considerations such as size, structure, and materials would require to be further explored along with the architectural scope.

7.2

Signage
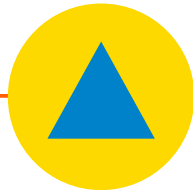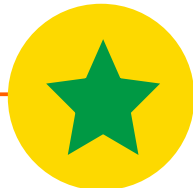
Checkpoint

- 3D
- Coloured
- Textured
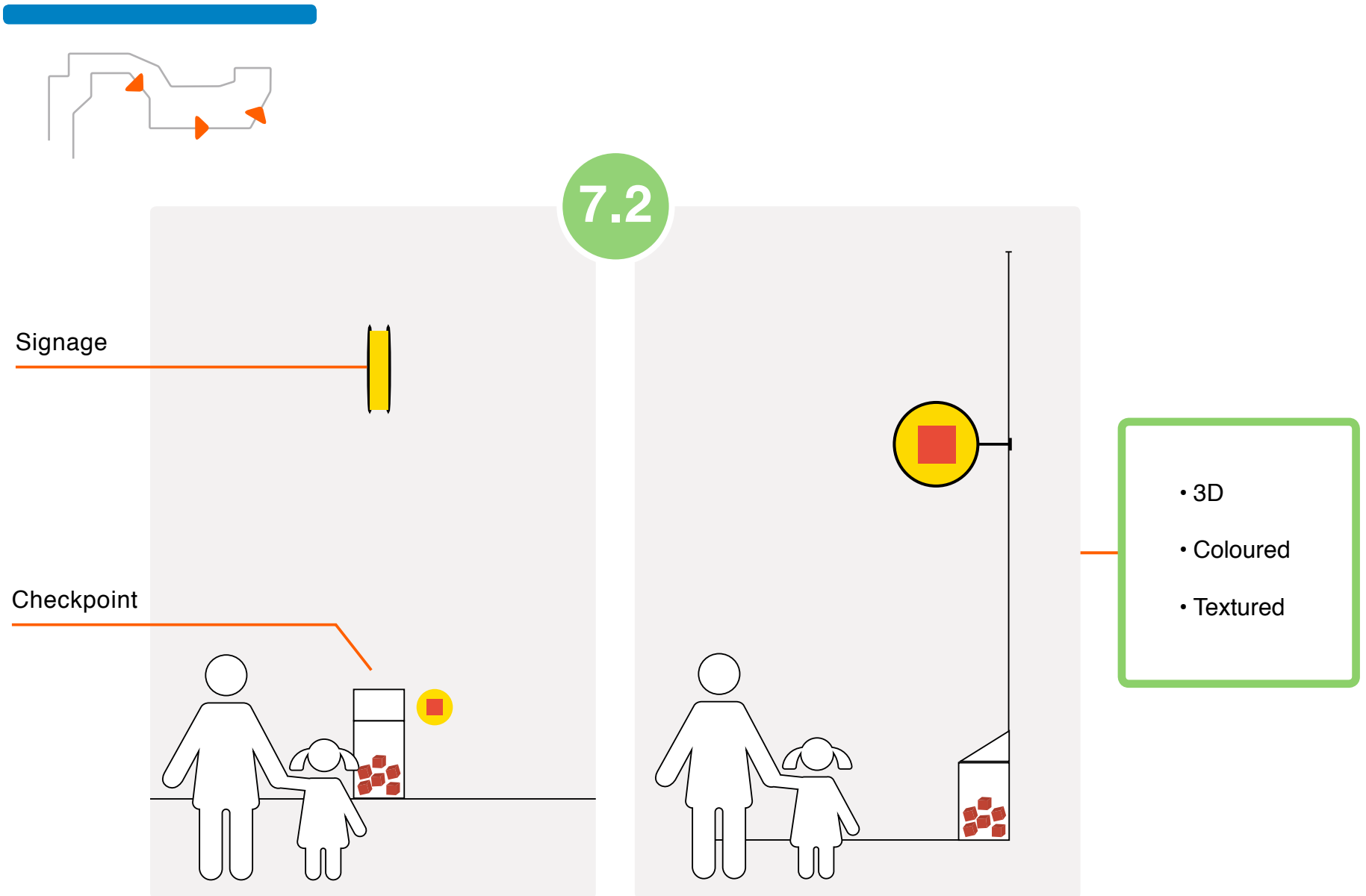
Figure 22. Recommended checkpoint design and positioning within the space.

CHAPTER 5:
CONCEPT DESIGN

8 **Poster: Checkpoint guidelines**

When participants were asked about the tools that they used to present new information to children with NDD/D, they responded that similarly to establishing routines, they broke information into specific steps. Through this method, they were able to introduce changes or new knowledge and manage the challenges that they would present.

Similarly, checkpoint guidelines (Figure 23) would provide children with NDD/D with the steps required to complete the activity at each stage. These posters would be aligned in its structure and content with the tools previously designed, and they would be located close to the geometrical shapes bins. The aim would be to engage children with NDD/D with the activity, feel secure, comfortable, and empower them to become more independent through play.

8

Signage

Poster

Checkpoint

Checkpoint #1: Reception

Great! You reach the first stop. These are the steps you need to follow:

You'll need:

Steps:

1 Photo — Description

2 Photo — Description

3 Photo — Description

Next stop: the waiting room!
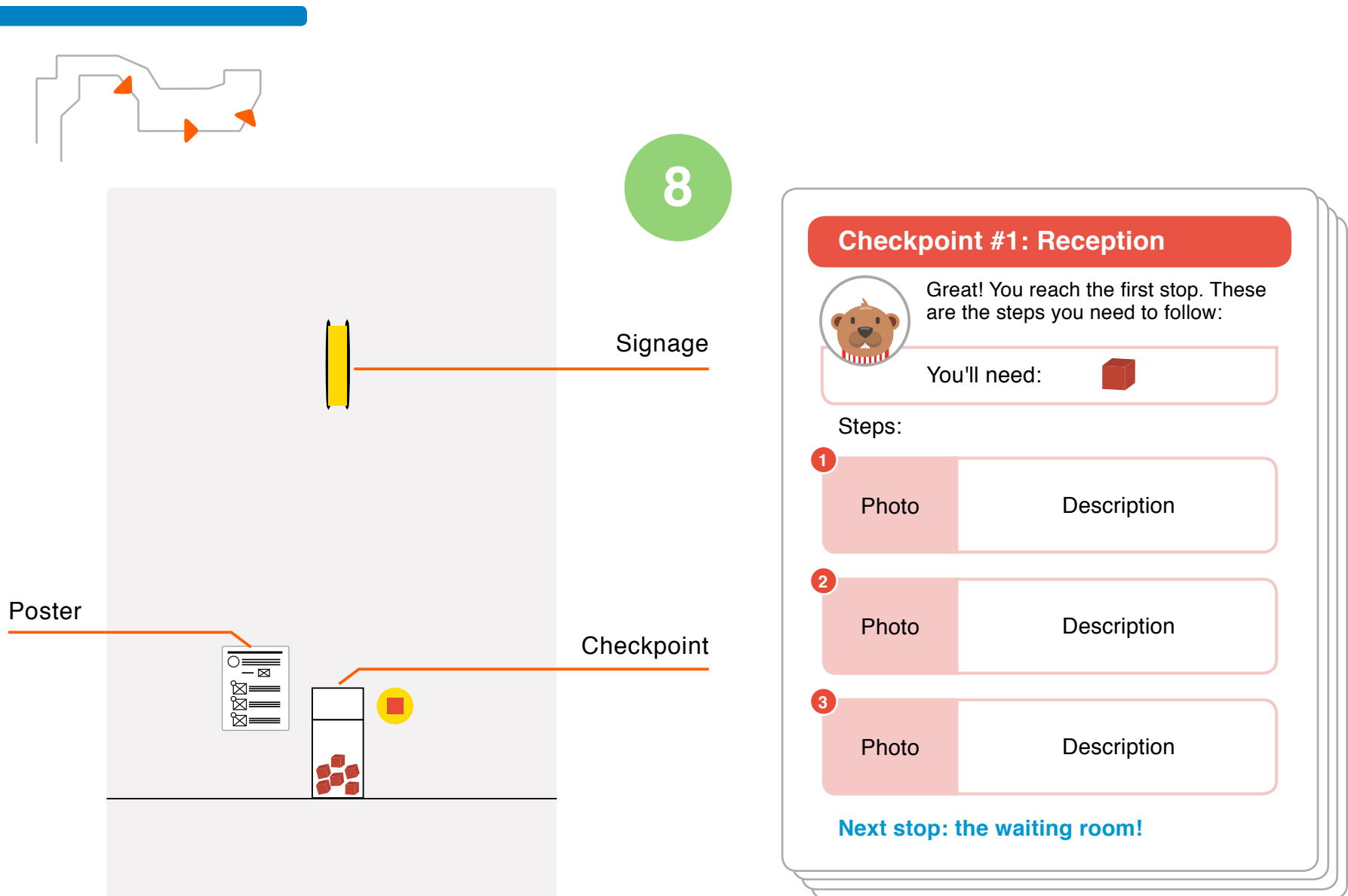
Figure 23. Recommended poster (checkpoint guidelines) design and suggested positioning within the space

CHAPTER 5:
CONCEPT DESIGN

Design Strategy: PHASE B - Recommended Tools

9 **Ribbon**

Participants expressed that when they did an activity with children with NDD/D, they tried to keep everything with a positive perspective from start to end as much as possible. They acknowledged that children with NDD/D needed to have a sense of accomplishment and recognition when the work or activity has been completed. Therefore, the intent to design a tool that would represent their accomplishment when finishing the treatment session (Figure 24).

A ribbon is an artifact that portrayed the symbolism of success for centuries. As Wikipedia describes, it is an award presented to mark an achievement. It can have different sizes, shapes, and can be built of different materials (Wikipedia 2020).

By designing four ribbon styles, we would give children with NDD/D the opportunity to choose based on their preferences. Ribbons would be made by texturized and colourful materials to engage their visual and tactile senses and recognize the accomplishment obtained in the day.

9

Design #1

Great Job!

Design #2

Design #3

You did it!

Design #4

Draw or write here

• 3D   • Coloured   • Textured
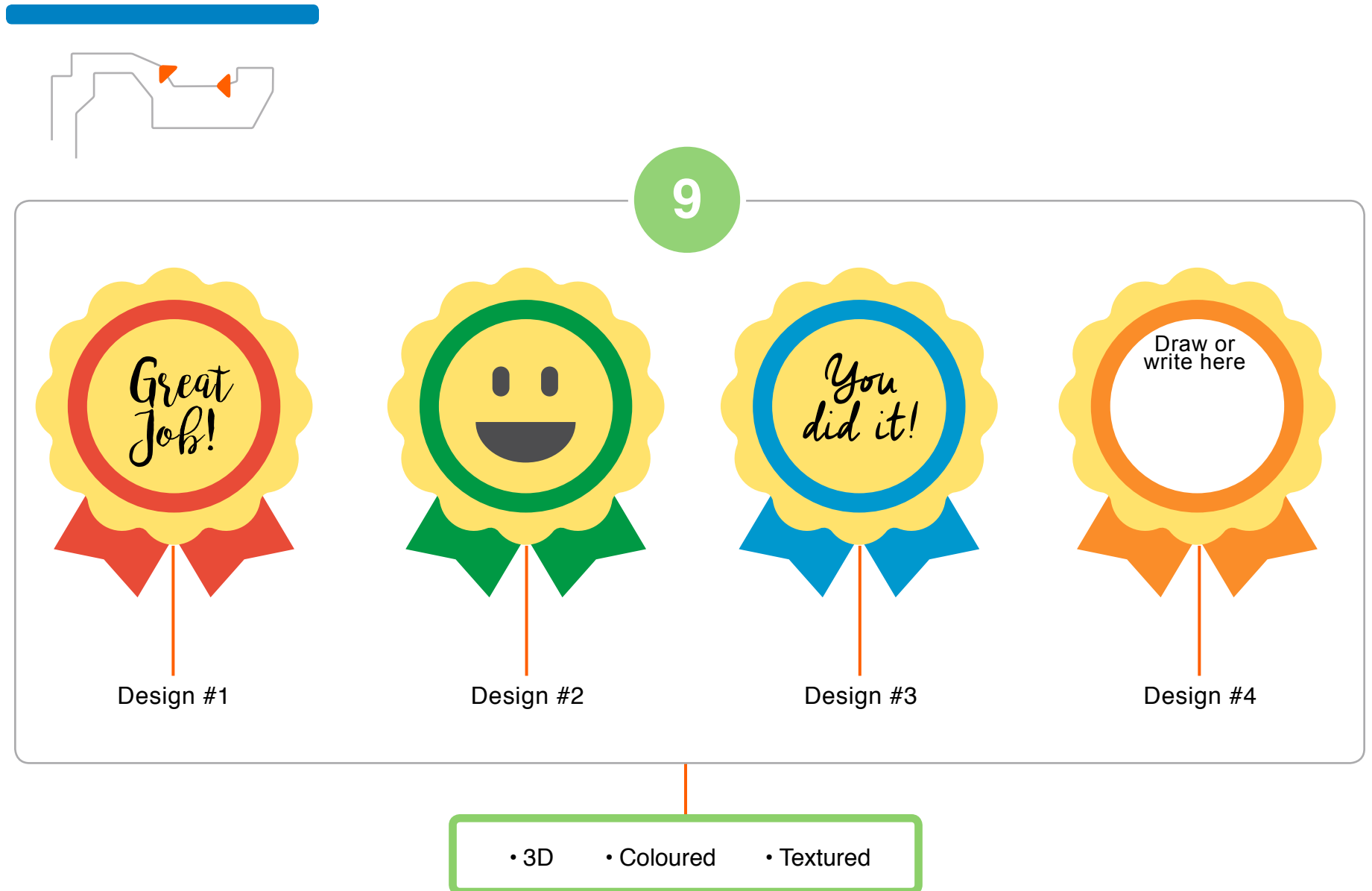
Figure 24. Recommended ribbon designs

CHAPTER 5:
CONCEPT DESIGN

10

10.1

Checkpoint - Wall design

This last checkpoint aimed to prepare children to exit the facility by acknowledging that all steps have been completed and the visit has finished. In contrast to the other checkpoints, this area would have a wall design (Figure 25) that would be similar to a ribbon silhouette. The objective would be that children with NDD/D place their ribbons inside the outlined shape. However, this would be an optional step considering that some children with NDD/D might prefer to take the ribbon home. Additionally, the dimensions of the wall design would require to be revised to reflect an adequate height suitable for all children.

Similar to other checkpoints, signage and a poster with guidelines would be close to the wall design in order to offer guidance to children with NDD/D and their parents/caregivers.

10.1

Checkpoint

Poster
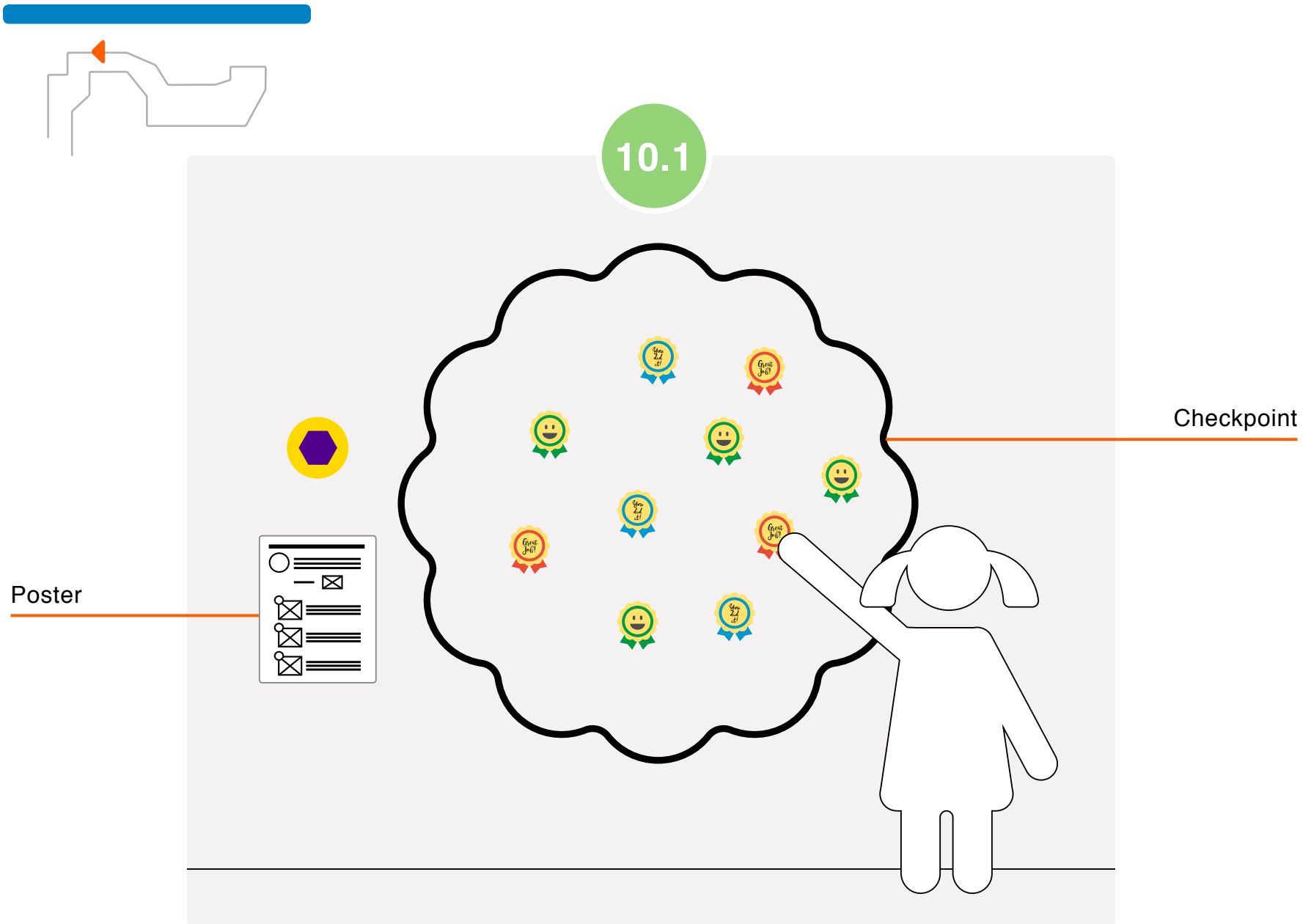
Figure 25. Recommended wall design and positioning within the space

CHAPTER 5:
CONCEPT DESIGN

10

10.2

Checkpoint - TSS Kiosk

A TSS kiosk (Figure 26) would be the second component of the last checkpoint. The purpose behind this tool would be to provide a convenient place to store TSS toolkits and give parents/caregivers the flexibility to grab them to be used on the next visit. The considerations for the packaging would be to keep a consistent style that matches the other tools, easy to handle, and use by children. The toolkit would include one infographic, one passport, and three objects with geometrical shapes. This last step would represent the end of the journey and the successful completion of the visit.

As previously described, this study had focused on the graphic and orientation elements. However, considerations in regards to size, structure, and materials required for the kiosk would need to be further explored along with the architectural input.

10.1

Exit

Checkpoint

Designed
Package
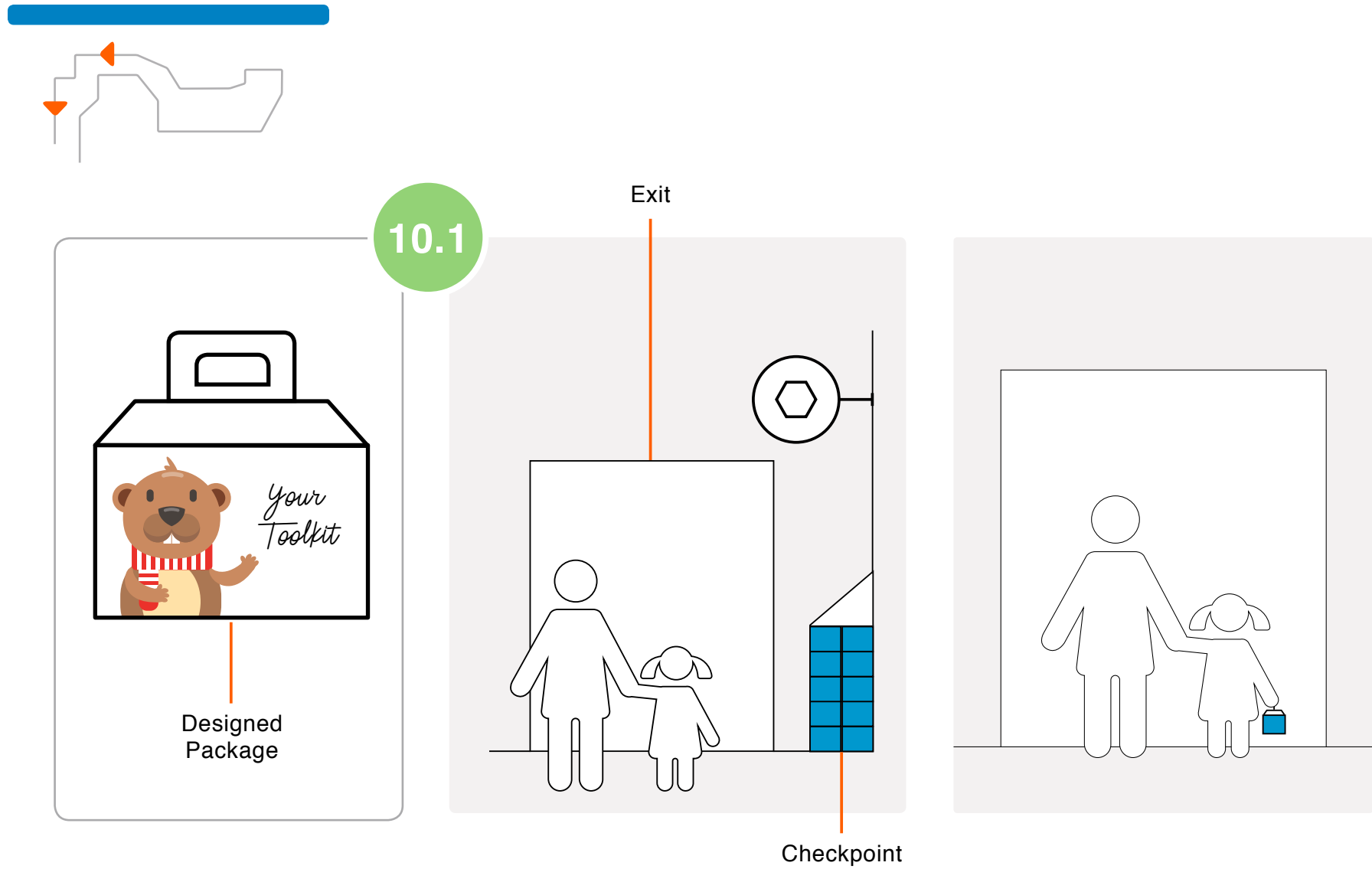
Figure 26. Recommended TSS toolkit packaging and positioning of TSS kiosk within the space

CHAPTER 6: DISCUSSION

Robust knowledge about transitions and the challenging behavioural and emotional effects that generate in children with NDD/D when visiting a treatment centre was gained through qualitative and quantitative research methods. Children with NDD/D, parents/caregivers, and health professionals' perspectives and experiences informed this study. The findings subsequently guided the design of a transitional support system that aims to help minimize transitional challenges, promote well-being, and create positive experiences for children with NDD/D.

Children with NDD/D, parents/caregivers, health professionals

As Figure 1 (Chapter 2) illustrates, children's development and growth depends on the support and care of parents/caregivers, as they represent their proximal environment. However, as Figure 8 (Chapter 4) indicates, the primary environment for children with NDD/D is consolidated not only by parents/caregivers but also by health professionals. Their surveillance is required to ensure children with NDD/D receive appropriate and timely services that promote healthy development.

According to Bowlby's Attachment Theory, primary relationships that are nurturing, responsive, and stable enable children to regulate their emotions and develop a secure base to explore, learn, and develop relationships with others (Bowlby, 1978). Similarly, studies in developmental psychology and child psychiatry affirm that a secure attachment to a primary caregiver is associated with healthy emotional and cognitive functioning in later life (Boris et al., 2000).

CHAPTER 6:
DISCUSSION

When analyzing the role of parents/caregivers and health professionals in children with NDD/D's lives, this study has concluded that they are facilitators of experiences. They are children with NDD/D's most reliable source of information and entities that promote trust and security. These are the aspects that this study aims to replicate with the transitional support system by designing tools that can become links that connect children with NDD/D and the environment, and establish a trustworthy relationship that promotes secure and positive experiences.

Importance of children's treatment centres

WHO affirms that an environment is an important factor in children's development; it represents the physical, social, and attitudinal setting in which they conduct their lives (WHO, 2007). In the case of children with NDD/D and their families, treatment centres constitute an immediate environment, as they require consistent access to health care services.

As Tuan states, children perceive places as large objects impossible to mobilize, and that can trigger different feelings. If an environment is hostile, children respond with challenging behaviours or emotions, and they look for their parents/caregivers' immediate support to feel secure. In the same way, children understand the sense of space as they grow. For instance, from two years old, children can recognize landmarks, signage, and associate people with specific spaces (Tuan, 2008).

Despite visits to treatment centres are frequent for children with NDD/D, they are constantly experiencing challenging behaviours and emotions throughout the journey. Considering the need to access treatment services to support children with NDD/D's development, this study identifies the importance of creating tools that can help minimize behavioural and emotional challenges, promote a secure and comfortable environment that children with NDD/D can enjoy and trust.

CHAPTER 6:

DISCUSSION

Children with NDD/D's journey and transitions

Contrary to the initial thought of considering children with NDD/D's journey as a process compound by before, during, and after stages, the findings generated in this study demonstrate that the process has two well-defined stages. As Table 2 illustrates, Phase A starts when children with NDD/D leave home and ends when they arrive at the treatment session. In contrast, Phase B (Table 3) starts when children with NDD/D leave the treatment session and ends when they return home. Both phases constitute two different processes with unique requirements and challenges, but when combined, create a single circuit that defines children with NDD/D's journey.

By identifying children with NDD/D's actions and movements from one environment to another at each phase, this study was able to determine low, moderate, and severe levels of transitional impact. The data gathered from health professionals at the co-design session informed the design of tools that meet the environment-action requirements and support children with NDD/D to minimize behavioural and emotional challenges caused by transitions.

CHAPTER 6:
DISCUSSION

The importance of creating a transitional support system

Based on the need of children with NDD/D to visit treatment centres on a regular basis, their journey and the transitional challenges presented, this study understood the necessity to create a transitional support system that can promote children with NDD/D' well-being and encourage a trustworthy relationship with the environment.

The design strategy is built on the necessity to have an effective resource that minimizes the behavioural and emotional challenges generated by transitions through creative tools that promote play, security, comfort, structure, guidance, inclusion, and positive experiences. In the same way, each tool aims to address specific challenges and connect with children with NDD/D in a subtle manner resembling the role of a transitional object throughout the journey. As Winnicott states, transitional objects have a soothing and comforting function, enlarge the child's real-world perception, and become a companion that they can trust and hold while entering new spaces (Grolnik et al., 1988).

The parameters that guide the design of tools were the result of the literature review and research findings. For instance, colour and textures management aimed to stimulate children with NDD/D's senses and promote knowledge. As Tuan states, sight and touch are the principal enablers of experiences within spaces (Tuan, 2008). Therefore, most recommendations intend to create 3D, textured, and colourful objects. A similar focus is given to the importance of play in children's life. No matter their abilities, children have the right to play and have fun (UNICEF, 1989). As Bundy affirms, play opens children's understanding of their surroundings and encourages learning about spatial relations through imagination (Bundy, 2012). Play becomes the link between two worlds: inside and outside, between psychic reality and external reality, between daily life and its caesuras (Grolnik et al., 1988).

CHAPTER 6:
DISCUSSION

Study Limitations

The study findings were based on an incremental process that expanded the knowledge at each stage of the research. A deeper insight into the behavioural and emotional challenges generated by transitions in children with NDD/D was enhanced, which promoted the development of the transitional support system, but many constraints appeared throughout the process.

Firstly, the number of children with NND/D and parents/caregivers that participated in semi-structured interviews and co-design sessions were limited. Secondly, the time allocation for the MRP, long travel distance and participants' availability lessened the opportunity to schedule a co-design session that could allow the prototype testing and feedback. Thirdly, in order to place signage appropriately within the spaces, architectural advice would be required. Consultations with Architects would help define the most suitable materials and appropriate dimensions to be used. Finally, bias is always inherent, but rigorous research can ensure that participant needs are always reflected.

Further Opportunities

The results generated in this study introduced several avenues for further research. For example, increase the scope of research to reflect the inclusion of children with and without variable abilities. Adapt the set of proposed tools to emerging new technologies such as apps and websites. Develop bidirectional communication channels between the health professionals and parents/caregivers in order to receive feedback about the effectiveness of the proposed tools for the transitional support system. Additionally, this study did not analyze the materials and implementation costs for the transitional support system. Therefore, further research is required.

CHAPTER 7: CONCLUSION

This study aimed to understand how a transitional support system can help children with NDD/D to minimize the behavioural and emotional challenges generated by transitions when visiting a treatment centre. Through the analysis of data gathered from quantitative and qualitative research methods, this study can conclude that visiting a treatment centre is a two-phase process characterized with a series of steps and transitions that present different levels of behavioural and emotional challenges in children with NDD/D. Additionally, this study identified that each step in the process should keep an adequate level of connectivity, continuity, and consistency to be effective and promote positive experiences for children with NDD/D and their parents/caregivers. Finally, the development of a transitional support system for children with NDD/D can help to create a secure and comfortable environment that will enhance better treatment results and well-being for them and their parents/caregivers.

Inclusive Design as Part of the Process

This study has been guided by the three dimensions of Inclusive Design developed by Jutta Treviranus (2018):

Recognize, respect, and design for human uniqueness and variability:

Children are complex and diverse human beings with unique abilities. They rely on the support and care provided by their parents/caregivers. In some instances, they might require extra medical support to achieve healthy development. Through the participation of children with NDD/D, parents/caregivers, and health professionals such as occupational therapists, physiotherapists, social workers, and speech-language pathologists, this study acquired an in-depth knowledge of how transitions can generate challenging behaviours and emotions in children with NDD/D, and the design of tools to support their well-being.

CHAPTER 7:
CONCLUSION

Use inclusive, open & transparent processes, and co-design with people who have a diversity of perspectives, including people that can't use or have difficulty using the current designs.

In order to understand children with NDD/D, parents/caregivers, and health professionals perspectives, this study relied on three main research methods that revealed participants' necessities, challenges, and expectations. Firstly, observations helped to determine the correlation between transitions and challenging behaviours/emotions. Secondly, semi-structured interviews promoted the knowledge of lived experiences and perspectives about treatment centres environments. Finally, a co-design session supported the identification of processes and the impact level of transitions throughout the visit to the treatment centre.

Realize that you are designing in a complex adaptive system.

Considering that children with NDD/D can be exposed to changing environments that trigger challenging behaviours and emotions generated by transitions such as changing schools, dentist appointments or social gatherings; this study presented a set of knowledge and tools that can be applied in different scenarios and promote children with NDD/D and parents/caregivers well-being.

The transitional support system can be defined as a framework to identify the actions and potential transitional challenges triggered by changing environments and develop tools that can support children with NDD/D to have better experiences throughout this process. Additionally, it promotes engagement, playfulness, security, trust, comfort, independence in children with NDD/D, and subtle connectivity, continuity, and consistency with the environment. These characteristics make this framework an important resource that could be used not only with children with NDD/D, but with other audiences such as children without variable abilities, adolescents, adults, and the elderly. Finally, transitions play an important role in any type of process, a transitional support system can help to manage them appropriately and increase the successful completion of a process.

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APPENDIX A: Observation Matrix

Users	Demographics	Predominant Visitors	Behaviours Profiles		
			#1	**#2**	**#3**
Visitor A	Children (1-10 years old)	Yes	• Calm • Communicative • Follow parents/ caregivers' guide • Eager to interact with the environment (e.g. sign-in by themselves)	• Shy • Not communicative • Stressed • Follows parents/ caregivers' guides • Not engaged with the environment	• Crying • Make Loud noises • Physical discomfort • Stressed • Not engaged with the environment • Hold by parents/ caregivers or in a stroller
Most recurrent visitors				Most predominant behaviour	
			Commonalities: Parents/caregivers guidance required		
			Commonalities: Not engaged with the environment		
				Commonalities: Stress and not being communicative	

APPENDIX A: Observation Matrix

Users	Demographics	Predominant Visitors	Behaviours Profiles		
			#1	**#2**	**#3**
Visitor B	Youth (11-21 years old)	No	N/A	• Shy • Not talkative • Follows their parents/ caregivers' actions • Not engaged with the environment • Interact with mobile devices	N/A
Visitor C	Parents/ Caregivers	Yes (children/ youth companions)	• Calm • Communicative • Positive attitude • Incentive the child to interact with the environment (e.g. let's sign-in at the kiosk)	• Attentive • Communicative • Eager to help the child • Incentive the child to communicate and express emotions (e.g. say hi to the receptionist)	• Tensed and stressed • Try to look for ways to communicate with the child and understand what he/she wants or needs • Apologetic for child's behaviour • Look for quiet spaces in the environment • Relies on the support of health care professional to control the child's behaviour
Most recurrent visitors				Most predominant behaviour	
		Commonalities: Try to be resourceful and communicate with the child			

APPENDIX A: Observation Matrix

Users	Demographics	Predominant Visitors	Behaviours Profiles		
			#1	#2	#3
			Commonalities: Calm and communicative		
Staff A	Health Professionals	Yes	• Calm • Helpful • Friendly • Incentive communication with children (Hi, Roger!)	• Calm • Helpful • Friendly • Incentive communication with children (Hi, Roger!)	• Calm • Helpful • Friendly • Incentive communication with child • Use play as an incentive to calm down the child • Support parents/ caregivers
			Commonalities: Calm, communicative, helpful, friendly, incentive communication with child		
Staff B	Administrative	Yes	• Friendly • Eager to help		
Staff C	Volunteers	No	• Friendly • Eager to help		

APPENDIX B: Questionnaire for Semi-structured interviews

SEMI-STRUCTURED INTERVIEW QUESTIONS

(5 minutes at the beginning for introductions and signing consent forms.)

About the Interviewee (10 minutes)

- Can you describe a typical day?

- What resources do you rely on the most? What are the relationships that are the most valuable to you? How much do you rely on other parents, online resources, on professional staff?

- Do you have a set of personal goals and/or milestones? How do you celebrate those? What are you the most proud of in your experience as a parent of a child with special needs?

About their Children (15 minutes)

- What is the diagnosis of your child?

- What are the major challenges you face?

- How do you manage those challenges? (Think about a time where you had a situation where you needed to use a different method to get a positive outcome.)

- How would you describe your child's behaviour?

- Does he/she like to be in a social environment or in a quiet space while waiting to be attended?

- What services and therapies does your child receive?

- Do you perform a specific routine before attending the therapies?

- What are your child's interests? How do they engage in these interests?

- Describe the type of things your child enjoys? (i.e. animals, colours, shapes, activities) What kinds of entertainment do you use for your child like to engage with? (i.e. TV, internet, books) What about digital devices?
- Does your child like to do art? If so, what kind? (i.e. materials, techniques)

About Grandview Kids (20 minutes)

- When did you start coming to Grandview Kids?
- How often do you come to the facility?
- When you arrive at the children's treatment centre, can you walk us through the process from beginning to end (for one visit)? (Look for what spaces they use the most)
- Is there a specific area you like the most? Why?
- How do you picture the new facility? (i.e. amenities, facilities, feeling, or quality of experience)
- What is the feeling or quality of the experience that you would like to have?
- How do you picture the different spaces at Grandview to look like? (i.e. amenities, facilities – based on Q3 ask about the spaces that they use the most)
- What do you find are the greatest barriers for you and your child at Grandview?

About Wayfinding (20 minutes)

- Are you able to quickly find rooms and services?
- Is the setup intuitive?
- Do you rely on signage or people to give directions?
- Could you describe your actions since arriving at the facility?
- Does signage help you to find information to reach your destination?
- Have there been times where you had gotten lost and unable to find your way within the facility? What do you do when you get lost or disoriented in the space?

- Does your child rely on your guidance to move between spaces?

- Is your child aware of the surroundings?

- What would your ideal way of getting wayfinding information be?

About Experience of Spaces (20 minutes)

- Is the setup intuitive?

- Does your child have a favourite place(s)? Why do they like it?

- Does your child have any sensory sensitivities? Are there any environmental factors that agitate your child or cause stress? (i.e. poor organization, loud noises)

- What are your current methods for coping with this?

- Are there any environmental factors that help alleviate stress? (i.e. placement of furniture, color, lighting)

- Are there particular types of furniture that your child likes?

- How do they usually use this furniture? What is the context?

- Are there particular types of materials or surface textures that your child likes?

- Do the spaces at Grandview allow you to form supportive networks and relationships with other parents, children and staff?

- If so, what spaces are the most important to forming those networks and relationships and why? How valuable has this been for you during your time at Grandview? (i.e. multi-use spaces that allow for events, close seating that allows for spontaneous conversations)

- If not, would you find it valuable? What type of spaces that are currently missing at Grandview that you would need to strengthen your networks and relationships? (particularly if you are part of a committee or attend workshops/events, are there issues in terms of space?) (i.e. semi-private spaces, spaces to gather and organize events)

Thank you!

APPENDIX C: Thematic Network Analysis - Semi-structured Interviews

Data	Pre -Themes	Basic Themes
Visual aids incentive playing in children	Visual aids incentive play	Visual Aids
Parents identify the space based on colours	Colours help navigation in a space	Visual Aids
First time users (parents) find it difficult to spaces without asking for guidance	First-time users require guidance	Visual Aids
Use signs with pictures to help children that don't know how to read	Visual aids to help children that don't read	Visual Aids
Children are sensory seeking	Children are sensory seeking	Visual / Tactile Aids
Any interruption in routines causes negative behaviours/stress	Changes in routines trigger negative behaviours	Diminish negative behaviours
Trying new things is difficult and produce anxiety	Trying new things produce anxiety	Manage communication effectively
Different therapy rooms can trigger negative behaviours	Changes in treatment rooms trigger negative behaviours	Diminish negative behaviours
He (the child) does what he is comfortable with	Children need to feel comfortable	Diminish negative behaviours
Children could cry and be upset	Children could cry and be upset	Diminish negative behaviours
Children require strong motivators if you want them to try new things, usually things that they like	Children need motivation	Motivating activities
We have defined routines. Breaking tasks into specific steps	Children need defined routines	Routines
Children like consistency. Things working and where they belong	Children need consistency	Consistency
Children rely on routines when visiting places	Children need defined routines	Routines

APPENDIX C: Thematic Network Analysis - Semi-structured Interviews

Data	Pre -Themes	Basic Themes
Any interruption in routines or with the people that they interact will cause negative behaviours	Interruptions in the routine triggers negative behaviours	Diminish negative behaviours
Children are driven by strong motivators to complete activities	Children need motivation	Motivating activities
Children need to be busy, otherwise they get distracted	Children need to be focused	Be focused
Children rely on parents to do sports as they do not have enough strength to complete them on their own	Children rely on parents support	Partnership
My child was diagnosed with birth stain language	Diagnosis	Diverse
He (the child) has difficulty in sensory processing and speech - mild developmental disability	Diagnosis, sensory processing	Sensory
He (the child) is sensitive to sound	Diagnosis, sensory processing	Sensory
Taking a whole new environment can be very overwhelming for him (the child)	New environments are overwhelming	Diminish negative behaviours
He (the child) has difficulty understanding directions or steps to take before an activity.	Challenges understanding directions or steps before an activity	Structure
Child gets upset when he is not understood (speech difficulty)	Children gets upset when he is not understood	Diminish negative behaviours
Child gets frustrated when he is not understood (speech difficulty)	Children gets frustrated when he is not understood	Diminish negative behaviours
He (the child) is unable to focus	Children are unable to focus	Diminish negative behaviours
He (the child) is fidgety	Children are fidgety	Diminish negative behaviours

APPENDIX C: Thematic Network Analysis - Semi-structured Interviews

Data	Pre -Themes	Basic Themes
He (the child) do not have good coordination	Children do not have good coordination	Diminish negative behaviours
He (the child) learns differently	Children learn differently	Learn differently
He (the child) is shy when visiting new places	Children are shy	Shy
He (the child) likes textures, squishy toys, sensory tables.	Children likes textures	Textures
He (the child) likes to play with cars (driving sensation) and iPad	Children like to play	Play
He (the child) likes being outdoors, keep moving	Children like to keep moving	Activity
He (the child) is good at following directions and follow specific steps	Children are good at following directions and specific steps	Structure
He (the child) needs consistency. Everything needs to be the same.	Children need consistency	Consistency
When he (the child) is stressed we use a weighted blanket, sensory toys or things that he can feel.	Use transitional objects to make him feel better	Emotional Support
He (the child) uses the trampoline to focus and lower the energy levels	Trampoline helps children to focus	Interaction
We use tools to cope with behaviours triggered by the environment such as headphones to control the noise, communication book to help with his speech, the stroller helps to save energy	Use objects to control behaviours triggered by the environment	Emotional Support
Parents like activities that children can interact with	Children like activities that they can interact with	Interaction

APPENDIX C: Thematic Network Analysis - Semi-structured Interviews

Data	Pre -Themes	Basic Themes
It is important to create positive associations with things/actions that they do	Create positive associations	Positive Association
Children need help accepting changes	Children need help accepting changes	Manage communication effectively
It would be nice to have activities/things that redirect the routes like leading towards the elevator or the stairs or something near the exit	Tools that help children to focus	Motivating activities
Make sure that the space consider children on wheelchairs	Consider children on wheelchairs	Functionality
We (parents) keep everything positive and end with a positive note	Create positive associations	Positive Association
We (parents) like to give the idea of: Yes! You did it! You tried something new and it was a lot of fun	Incentive the feeling of accomplishment and having fun	Have fun
Rather than avoiding certain activities, we (parents) try to expose him to the elements so they can get used to them and modify them when required	Get use to things by exposure	Exposure
We (parents) look to learn about the environment and try to find the best ways to support the child.	Find the best ways to support the child	Diverse
When visiting new places, we (parents) arrange a preview visit to the space and get to know the activities that will take place there, so he can see it too.	Previsualize spaces and actions to be taken in an environment	Manage communication effectively
We (parents) want to diminish as much as possible negative behaviours in the child and we have worked so hard to get him to be like managing on his own.	Diminish negative behaviours	Diminish negative behaviours

APPENDIX C: Thematic Network Analysis - Semi-structured Interviews

Data	Pre -Themes	Basic Themes
We (parents) would like environments that give tools like mazes that help slow down the children and help them to focus	Tools that help children to focus	Motivating activities
We (parents) tend to not change established routines, as it is hard to add changes in his routines and could be difficult to overcome the effects especially if they were negative	Do not change established routines	Routines
When we (parents) introduce a change, we have to specify the details, point out the differences from the other activity in order for him to understand why that specific action works in a specific way	Need to specify details and point differences to introduce a change	Manage communication effectively
We (parents) rely on behaviour management and keep saying positive reinforcement. Get him to do a task has to be associated with positive reinforcement	Develop positive reinforcement	Positive Association
We (parents) rely on the information and advice from therapists. Good communication is necessary	Good communication between parents and therapists	Partnership
When we (parents) went on vacation, we created a communication book with the specific activities, characters, food, rides that we were going to see	Need to specify details and point differences to introduce a change	Manage communication effectively
For us it is important to create tools that allow him to feel confident. We can see the improvement in his speech and he just blossomed with that kind of support	Children need to feel confident.	Security

APPENDIX C: Thematic Network Analysis - Semi-structured Interviews

| Data	Pre -Themes	Basic Themes
We (parents) rely on social stories when visiting a new place so children feel more comfortable when they go there otherwise you are wasting their energy.	Previsualize spaces and actions to be taken in an environment	Manage communication effectively
We need just a basic social story that shows what to expect when you go especially for a parent, a new family. It is not only good for the kid but for the parents to know how to prepare	Get information beforehand about what to expect and how to prepare	Manage communication effectively
We would like the new space to have solid and nice colours	New space with solid and nice colours	Consistency
The furniture should have consistent colours and shapes	Consistent furniture	Consistency
Consider users with wheelchairs	Consider children on wheelchairs	Functionality

APPENDIX D: Co-Design Guide and Tools

Photo by BabyCenter.com

PETER

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Age:	5 years old
Gender:	Male
Challenges:	Cognitive and sensory impairments
Status:	Inpatient
	Visits the Children's Treatment Centre 3 times per week for treatment sessions.
Location:	He lives with his family in Whitby and his mom drives 45 mins to Oshawa in order for him to receive the treatment sessions.
Interests:	He likes playing with toys and his sister.
	He likes reading books.
	He likes to play sports with his dad specially outdoors.
	He likes to play games or watch videos on his tablet.
	He is a happy kid, very creative, a bit shy when meeting new people, likes structure and rules, he's eager to explore new things sometimes.
	He relies on his mom as she takes care of him everyday.
Goal:	Define his journey before, during and after the visit to the Children's Treatment Centre.
	Identify the transitions that produce more anxiety for him.
	Determine the tools that can help him to transform negative emotions/behaviours into positive transitional experiences and achieve better treatment outcomes.

Pieces
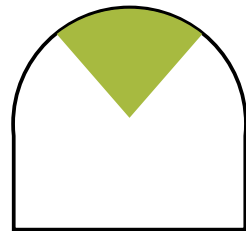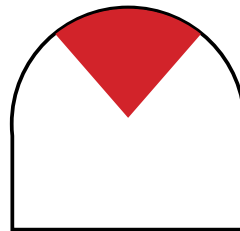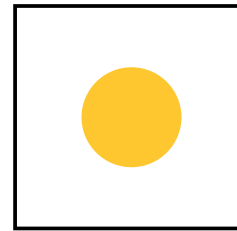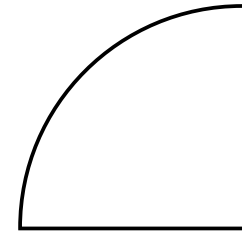
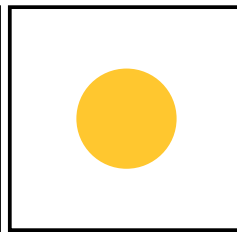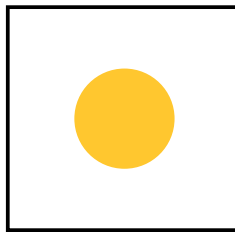| Start	End	Steps	Transitions

Identify the journey
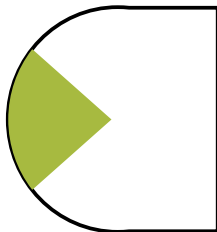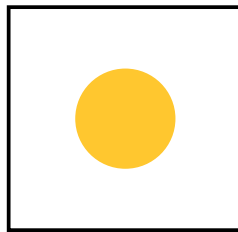
Start	Go to the washroom	Take a shower	Get dressed	Go to eat breakfast	End
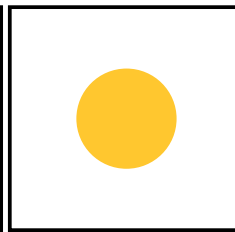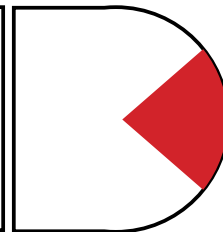
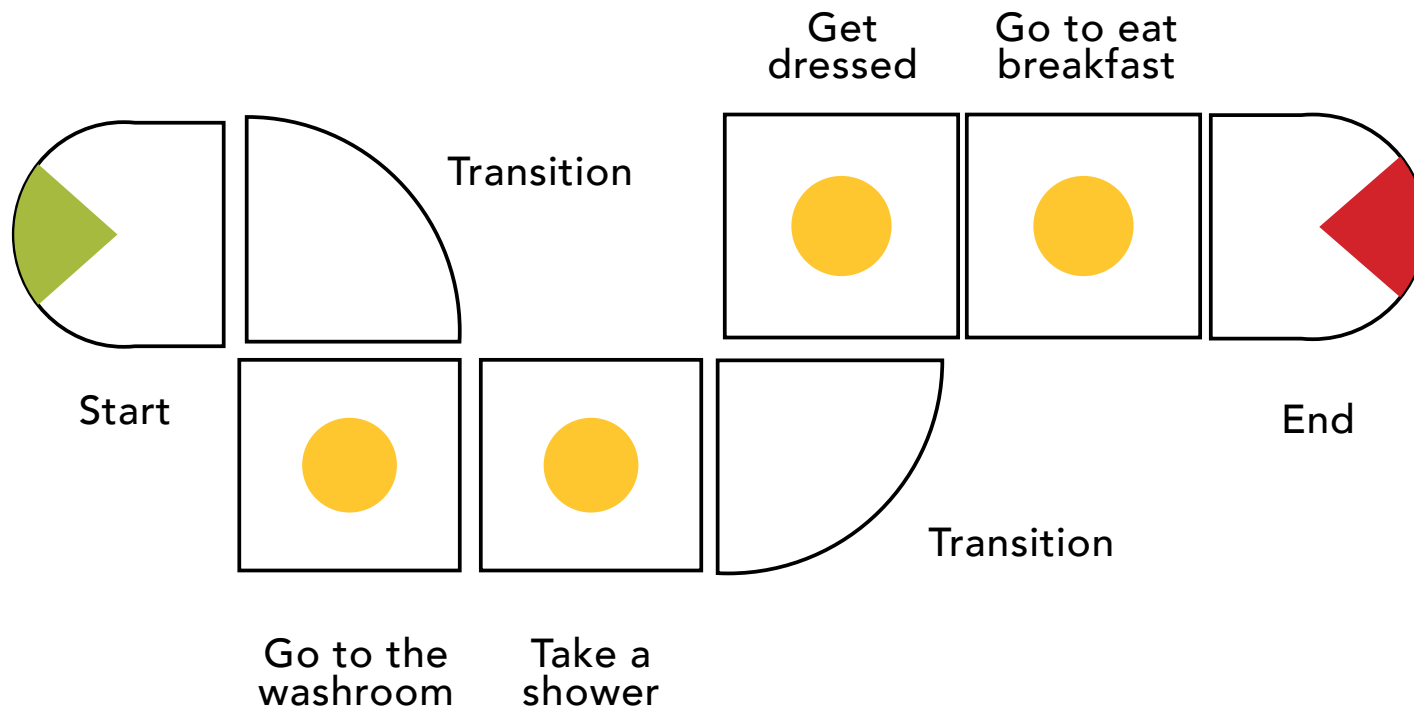# Identify transitions within the journey

Start

Transition

Get dressed

Go to eat breakfast

End

Go to the washroom

Take a shower

Transition

Identify transitional impact level

Start

Transition High

Get dressed

Go to eat breakfast

End

Go to the washroom

Take a shower

Transition High