So close, too far: Co-designing meaningful mothering experiences through products with

mothers living with SCI

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Abstract

There is a significant gap in the current literature to investigate the construction of meaningful mothering experiences with Spinal Cord Injury (SCI). This research applied co-design practice to explore the construction of meaningful mothering experiences through the interplay between mothers with SCI and child-caring products in the home environment.

The first research cycle specifically focused on the experience of mothering with SCI and their challenging activities in the home environment. The findings of Cycle I highlighted that there was a difference between the mothers' physical challenging activities and their meaningful mothering experiences. The findings from Cycle I were applied in Cycle II to better understand the construction of meaningful mothering experiences. The findings of Cycle II revealed the mothers' interest in using a product instead of relying on a third party in their mothering activities. From the mothers' perspective, mothering was described as being more than just performing physical tasks, but also a way to express their love to their child. Furthermore, the lack of products which met the mothers' needs led to limited opportunities for them to interact one-on-one with their child. The mothers' interest in using a product in mothering activities broadened my focus from only concentrating on child-caring products to products/ furniture in their home environment. Consequently in Cycle III, I explored how products/ furniture could be used to help create more frequent meaningful mothering experiences in their home environment. The mothers' interest in a one-on-one engagement with their child on the inaccessible floor drew my attention to focus more on 'fit' furniture in their home environment. Based on the research findings and co-designing with the mothers two prototypes of the idea of 'fit' chairs were developed and shared with the mothers in Cycle IV. According to the findings of Cycle IV, a product which meets the mothers' needs has a high potential to turn a heart-breaking mothering experience into a meaningful mothering experience.

My findings also demonstrate how the misfit interaction between bodies and material environment can impact on the construction of meaningful mothering experiences with SCI. According to the research findings, the social construction of an 'able-bodied' mother and applying the normative approach in product design led the mothers to fit themselves to a misfit environment.

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List of Abbreviations

ACC   Accident Compensation Commission

CAD   Computer Aided Design

CAM   Computer Aided Manufacturing

CNC   Computerized Numerical Control

IDSA   Industrial Designers Society of America

PAR   Participatory Action Research

PrEmo   Product Emotion

SCI   Spinal Cord Injury

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signature

Date

Acknowledgement

Ethical approval was obtained from the Auckland University of
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Chapter 01. **Introduction**

Introduction

This PhD research explores the interplay between mothers living with SCI and child-caring products in their home environment. The word 'interplay' in this research refers to the way the mothers interact with a product and the effect a product has on the mothers.

As a design researcher, I am specifically interested in the role of products to create meaningful experiences for mothers living with SCI throughout their everyday lives. The motivation to embark on this research journey was my interest in the area of design and disability, and the potential for design to improve meaningful experiences for disabled people. Given that "an experience is a story, emerging from the dialogue of a person with her or his world through action" (Hassenzahl, 2010, p 8), in this research I focused on the stories of mothers with SCI and the construction of their mothering world through products. In particular, I aimed to explore the role of child-caring products in the construction of meaningful mothering experiences with SCI. In this research a meaningful mothering experience referred to an experience that was described by the participants in the research as an intimate and continuous relationship between a mother and her child.

1.1 Background and positioning myself as a design researcher

I position myself as a transdisciplinary[1] design researcher, and have a deep interest in design and disability. I was initially

[1] Transdisciplinary research refers to "a dialogue between two disciplines and frameworks, which may lead to a development of both through a process of each internally appropriating the logic of the other as a resource for its own development" (Chiapello & Fairclough, 2002, p. 186).

interested in studying product design because of the diversity and creativity associated with the discipline. Product design is the field of creating concepts and developing the function, value, and aesthetics of products, with the aim of improving user experience. In this research, I applied Boradkar's (2010) definition of product:

> the term "product" derived from Latin *productum*, which also refers to something produced; a product is the end result of a process. Product is a term primarily employed in design and engineering. As an artistic good, an artifact may often be produced by craft, while products, in most cases, rely on mechanized modes of manufacture. Inherent in this definition of products is the understanding that they exist in identical, multiple copies as they are manufactured in large quantities. (p. 24)

Prior to embarking on this research journey, I was a design researcher and taught product design at Tehran University in Iran for over eight years. My academic passion is for creativity within the design process, particularly when creative thinking is underpinned by a foundation of participatory design. I believe that creativity plays an essential role in identifying new ways of looking at design problems and that new design solutions should be created by user's participation, as the experts of their experiences, through the design process (Sanders & Stappers, 2008).

At the start of this research journey, I believed that there was an opportunity for a new way of looking into the needs of disabled people that could lead to addressing these needs more effectively. My interest in the area of product design for disabled people stemmed from the recognition that the product design discipline has focused less on addressing the needs of disabled people than those of able-bodied individuals.

In response to my interest in design for disability, I have previously undertaken several design projects for disabled people. The feedback I received from the participants in these design projects encouraged me to focus on product design for disabled people in this research. For example, in Iran I patented[2] a multifunctional device for people with double hand amputation. This multifunctional tool is a small and simple device that includes a base and a joint to connect to different products such as a toothbrush, spoon, or comb. The feedback that I received from blind participants with double hand amputation indicated that the device gave them confidence and a sense of achievement resulting in them having better control over their bodies. Receiving such feedback encouraged me to think more deeply about the role of products to improve the experiences of disabled people.

I also designed an assistive writing device for people with SCI who have dexterity difficulties. Similar to the other design projects for disabled people, from the participants' feedback I came to realise that the design of simple yet effective products that are specifically aimed at addressing the needs of disabled users can significantly improve their experiences with daily activities. The participants' feedback made me think about the disabling role of products for disabled users. While products are designed to facilitate people's daily activities, when they are designed to fit able-bodied people, they are disabling rather than facilitating the daily activities of disabled people.

Garland-Thomson's (2011) concept of misfit sheds light on the inconvenient interplay between human variation and the material environment. According to Garland-Thomson (2011),

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[2] Registered number A/82:001594.

"Fitting and misfitting denote an encounter in which two things come together in either harmony or disjunction" (p. 592). The misfit concept views disability as a way of arranging a body in the material environment. The concept of misfit shifts focus from the individual to the interaction between the body and the material environment (e.g. product, device or building). According to the concept of misfit, disabled people have to fit themselves to the material environment instead of having access to a material environment that fits their bodies.

Garland-Thomson (2011) claims that the theoretical application of the terms 'fit' and 'misfit' derives from their rich meaning, both semantically and grammatically. She says, "according to the *Oxford English Dictionary*, the verb fit denotes a relationship of spatial juxtaposition, meaning 'to be of such size and shape as to fill exactly a given space, or conform properly to the contour of its receptacle or counterpart; to be adjusted or adjustable to a certain position'" (p. 592). Garland-Thomson (2011) also adds: "Misfit, in contrast, indicates a jarring juxtaposition, an 'inaccurate fit; (hence) unsuitability, disparity, inconsistency,' according to the Oxford English Dictionary. Misfit offers grammatical flexibility by describing both the person who does not fit and the act of not fitting" (p. 594). In my research, I use the term 'fit' product to refer to products that meet the needs of mothers with SCI.

I believe there is much more that can be done for disabled people through product design and improving their everyday experiences, in particular for women. According to Garland-Thomson (2013) the intersection of categories such as gender, disability or race results in the cumulative impact of these categories. For instance, a disabled woman may be more stigmatised because of the intersection of gender and disability.

Earlier studies (Dillaway & Lysack, 2015; Wheaton & Crimmins, 2016; Clark & Mesch, 2018; Blum, 2020; Wheaton & Crimmins, 2016) reveal various social barriers such as

marginalisation, social exclusion and discrimination that disabled women face in societies worldwide. As a consequence of patriarchal societies, women with disabilities are more stigmatised and marginalised than men with disabilities (Garland-Thomson, 2002, 2005; Chanzanagh, et al., 2012; Don et al., 2015). Through this research, I aimed to explore mothering experiences of women with SCI through design for women, with women, and by women.

My strong desire to design with a marginalised group of disabled women led me to focus more specifically on the area of feminism as a concept to underpin my thinking. Despite my initial hesitation about feminism, I started to read more on this topic. Gradually, I saw a new window opening in my life. Although I believed that historically men have been more privileged, I was still sceptical of feminism as an idea or concept. I think that my doubts about feminism may have come from my background, as I grew up in a patriarchal society and had learned about feminism as an anti-male

movement. Moreover, the great respect and compassion that I had received from the men in my life (especially my father, husband and several of my colleagues) made me question the essence of feminism. I recognise now that this was an overly simplistic understanding of feminism. As I became more interested in feminism I was able to better understand my own life experiences and relationships in a new and more insightful way.

Feminist epistemology challenges traditional ideas and shows how patriarchal social arrangements constrain the life choices of women. Subsequently, engaging with feminist concepts helped me gain a better understanding of the notions of gender equality and power relationships, beyond my personal experience within my own family, to explore how these play out in broader society. By doing this PhD through a feminist lens, I was able to strengthen my critical-thinking skills. This PhD journey has also helped me to reinforce my voice and give me the courage to argue for my own opinions. As a

consequence, I have been able to reflect on many different aspects of my life, and have realised how patriarchal systems have also frequently caused me to experience discrimination. I have recognised that I have often had to prove myself and my abilities as a female product designer beyond what was required by my male counterparts. This was because I was prejudged to have fewer skills and less technical knowledge in my field of work because of being a woman.

While in the past I had accepted that I was required to prove myself as a female product designer, I had never asked myself why this was the case. For instance, I was a product design lead at FanForm Company in Tehran, Iran. The CEO of the company was also a female product designer. The focus of our design projects was on health and wellbeing. I recall a day I and the CEO had a meeting with the manager of one of the most well-known hospitals in Tehran. I could see disappointment and frustration in the manager's eyes when he saw us. We started to discuss the project we intended to do.

The design project was to renovate the emergency ward. Our proposal for this project was selected out of a number of other proposals through a long and competitive process. The final step was a meeting with the manager. To me, it was more like an interview to prove our ability as female designers and persuade him that we could tackle the project.

During the meeting, the manager asked us many times, doubtfully, "So you claim that you can do the project?" We replied, "Sure, we can." Finally, we got the project but with the condition in the contract that we would receive our payment when the whole project was done (i.e. after eight months) which was not the usual procedure. It was normal to receive a percentage of payment during the project, based on the timetable and mutual agreement. The project was done in good time but we received our payment almost a year after the due date. We accepted the project because we were determined to prove ourselves, because we were used to being

discriminated against, and because we did not have a voice to argue for our rights.

As a mother of two young children, based on my own experience of mothering and the challenges that I had during these times as an able-bodied woman, I anticipated that design could address the needs of mothers, and in particular those who live with SCI, more effectively. For instance, the nights when both children were sick and needed care, and I had to get out of my bed, go to their bed, give them their medicine or check their temperatures and go back to my bed; the days that the children and I enjoyed playing on the floor; and the many times that I picked up Lego and toys from the floor: I asked myself how product design could facilitate caring for their child, for mothers using a wheelchair.

I see this work as a personal journey of self-discovery, as well as knowledge development. For instance, in the first research cycle, when one of the participants identified as a lesbian, I found that I had been influenced by the normative approach to being a mother and I had never thought about lesbian mothers. Given that I have never talked with a lesbian mother about their experience of mothering, I attempted to be open to this experience and interview the mother with non-judgemental eyes. I found the mother's ideas and experiences very insightful. In the next research cycles, the mother's contribution was also very helpful. This interview made me think again about how the normative approach to mothering can influence the experience of mothers who do not fit the stereotype.

The more I read about feminism, the more questions I had, and the more I focused on addressing those questions, the more I learned about how feminism attempts to achieve women's social, political and economic equality to diminish gender discrimination (Garland-Thomson, 2002, 2005; Hesse-Biber, 2013; Lam, 2015; Swirsky & Angelone, 2016). Having gained such perspective, I began to question myself as a female designer to determine how product design could create new

opportunities for mothers with SCI to construct meaningful experiences.

Thus, the journey of this thesis began…

1.2 Dual potency of feminist disability theory and co-design

In this research, I focused on the intersection of feminist disability theory and co-design to explore the experience of mothering with SCI (Figure 1.1). The overall purpose of my research was to explore the construction of meaningful mothering experiences for mothers with SCI through co-designing 'for women, by women and with women' approach.
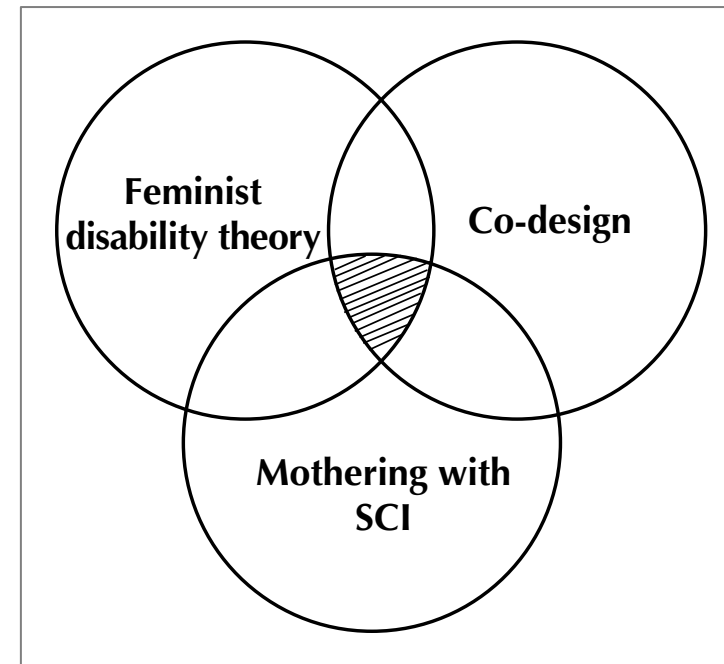
Figure 1.1. In this research I explored the intersection of feminist disability theory, co-design and mothering with SCI.

The intersection of feminist disability theory with co-design enabled me to explore more deeply the underlying experiences and issues associated with mothering with SCI, which were not apparent when approaching the mothering experiences from only a single-discipline perspective. As a result, it was anticipated that through this research new questions, theories and methods in different academic disciplines including design would be explored and developed.

Feminist disability theory stands against the objectification of women, and thus attempts to destigmatise all women by respecting their diversity (Garland-Thomson, 2002, 2005, 2011). Feminist disability studies view human variation as a complex collection of diverse individuals (Garland-Thomson, 2002, 2005; Hall, 2002; Mays, 2006). Feminist researchers avoid hierarchical research processes; thus, they attempt to maintain a power-balanced relation between a researcher and participants (Gatenby & Humphries, 1996; Hammersley,

1992; Lennie et al., 2003). In the same way, participants are considered as the experts of their experiences in co-design processes (Sanders & Stappers, 2008). Hence, participants are invited to work collaboratively with designers and researchers during a democratic way of knowing. Given that feminist disability theory and co-design both aim for social justice by respecting people's diversities, there was a possibility that the integration of feminist disability theory and co-design might enhance the design process by exploring the experience of mothers with SCI from a feminist epistemological position.

Few studies have documented the experiences of disabled mothers. The existing literature highlights the way society and material environments have made mothering for mother with disabilities more challenging (e.g., Guerin et al., 2017; Kaiser et al., 2012; Payne & McPherson, 2010; Prilleltensky, 2003; Thomas, 1997). According to the literature, there is a lack of products that can be used by mothers with disabilities to facilitate their ability to care for their child in Aotearoa New

Zealand (Guerin et al., 2017; Payne & McPherson, 2010). In addition to the limited available studies, there appeared to be a gap in the literature around the role of products to construct meaningful mothering experiences for women with SCI using a collaborative design process.

Mothers living with spinal cord injury have been selected as the participants for this research project because of the following reasons:

- Most of the research related to spinal cord injury has focused on health issues and rehabilitation spheres. Few researchers have explored the experience of mothering with SCI. There was little to no data to explore the interplay between mothers living with spinal cord injury and child-caring products.

- There was a high chance of finding 'designable solutions' to address this issue rather than using

medical interventions to diminish the consequences of spinal cord injury.

- Given my previous experience in designing an assistive device for people living with SCI, I believed that this area of research fit well within my interest and experience.

Spinal cord injury can result in loss of control of body movements and sensation function below the level of injury. According to Ray (2005) depends on the level of spinal cord injury the following neurologic damage can occur (p. 351):

- Below C4: loss of motor and sensory function from the neck down, including independent respiratory function and bowel and bladder control

- Below C6: loss of motor and sensory function below the shoulders; loss of bowel and bladder control; impaired intercostal muscle function

- Below C8: loss of motor and sensation to parts of the arms and hands; loss of bowel and bladder control

- Below T6: loss of motor control and sensation below the mid-chest but with motor control and sensation preserved in the arms and hands; loss of bowel and bladder control

- Below T12: loss of motor control and sensation below the waist; loss of bowel and bladder control

- Below L2: loss of motor control and sensation in the legs and pelvis; loss of bowel and bladder control

- Below L4: loss of motor control and sensation in parts of the thighs and legs; loss of bowel and bladder control.

The purpose of the thesis was, using a co-design practice component, to gain insights and contribute to knowledge regarding the construction of meaningful mothering experiences for mothers living with SCI. To contribute knowledge to these areas, my study sets out to explore the following research questions:

- How do mothers living with SCI construct meaningful mothering experiences?

- How might product design to construct meaningful mothering experiences for mothers living with SCI?

1.3 The outline of the thesis

This thesis consists of nine chapters. Following this introduction, Chapter 2, reviews relevant literature on mothering and disability, and product design for disabled users. The aim of the literature review was to identify potential gaps in the literature and to highlight the need to address those gaps. This chapter reveals that while studies have explored aspects of social and physical barriers for disabled mothers, the area of the construction of meaningful mothering experiences with SCI using products had been not sufficiently explored. Therefore, this chapter stresses the importance of exploring the potential of products to construct meaningful mothering experiences with SCI.

In Chapter 3, I discuss the methodology of my research. This includes presenting the research paradigm and an introduction to the feminist disability theory that has been used to underpin my approach. Since in this research, I applied Participatory Action Research (PAR) as an overarching methodology within four distinct but related cycles of collaborative activity, I provide a description of the PAR methodology. The application of PAR and feminist disability theory provided me with a lens to better explore the experiences of mothering with SCI with an approach of designing for women, with women, and by women. Finally, I present the trustworthiness and ethical considerations of my study.

In Chapter 4, I describe the research methods used (i.e., semi-structured interviews and co-design), as well as provide an introduction to the research participants. Then, I present a description of data collection procedure in each research cycle. Finally, I describe the analytical stages used for the data.

In Chapter 5, I present the finding of the first research cycle. In Cycle I, I initiated the research by exploring the challenging activities and meaningful experiences of mothering with SCI through the use of semi-structured interviews. The most significant finding of Cycle I was to highlight a difference

between how the mothers with SCI perceive a challenging activity and what constitutes meaningful mothering experiences for the mothers with SCI.

In Chapter 6, I describe the findings of the second research cycle, to show how the mothers with SCI construct meaningful mothering experiences. The aim of Cycle II was to gain a deeper understanding of the construction of meaningful mothering experience with SCI. In Cycle II, I found that mothering activity was not only a physical task, but also a 'love language' for the mothers to express emotions to their children. The analysis of data highlights that the mothers' need to rely on a third party (i.e. a mother's caregiver), which can interrupt this love language. The findings of Cycle II also revealed the mothers' interest in using a product instead of relying on a third party.

In Chapter 7, I present the finding of Cycle III. In this cycle, I focused on finding new opportunities for the mothers to use a product instead of relying on a third party in their home

environment. The findings of Cycle II shifted my focus from only child-caring products to a broader area including any 'fit' product/ furniture in the home environment. Hence, in Chapter 7, through co-designing with the mothers, I explored the characteristics of 'fit' products/furniture as well as the meaning construction of 'home' from the mothers' viewpoint. Finally, I present my ideas and concepts as my design response to the research findings. This is followed by a discussion of the processes of sketching, idea development rapid prototyping used to bring form to the ideas/concepts explored in this research.

In Chapter 8, I describe the process of the fourth cycle of the research. The aim of Cycle IV was to give further voice to the mothers and receive their feedback on our co-design process, as well as the prototypes that were made based on the findings of Cycle III. In Cycle IV, I found that 'fit' products have the potential to turn a heart-breaking mothering experience into a meaningful one. In addition, I found co-design as a useful

method to translate the mothers' unmet needs to a meaningful mothering experience experiences by giving voice to the mothers as the expert of their experience. The findings also show that a tangible outcome (i.e., physical prototype) made the co-design process more meaningful for the mothers.

In Chapter 9, I discuss the findings of this research in the context of the related literature. That is, I discuss how the integration of feminist disability theory and co-design provided me with a lens to explore the unmet needs of the mother with SCI. The research findings also highlight the potential for products to help construct meaningful mothering experiences for the mothers with SCI by providing them with new opportunities to improve the mother-child bonding.

Chapter 02. Literature Review

Introduction

Given that this research explores the construction of meaningful mothering experiences for mothers living with SCI through the interplay with child-caring products, this chapter starts by exploring the meaning of mothering in section 2.1. From there, I review the findings of earlier studies on mothering and the impact of the social construction of mothering on women's experiences. I then present the review of the studies on mothering and disability. In doing so, I focus on the experience of disabled mothers and the impact of social and material barriers on their experiences of mothering. In section 2.2 I present the literature that discusses previous attempts in product design practice to address the needs of disabled users and also seek to discover how a normative

approach to the body can impact the way design has responded to disabled users.

2.1 The meaning of mothering

The literature highlights feminist scholars' challenge to the essentialist[3] approach to women and mothering (Arendell, 2000; Bassin & Kaplan, 1996). In the essentialist approach, motherhood is an integral part of women's life and the notion of motherhood is tied to the female gender (Cowdery & Knudson - Martin, 2005; Hays, 1996; Kretchmar & Jacobvitz, 2002). Snitow (1992), by reviewing more than 100 publications on feminism and motherhood from 1963 to 1990, identifies three periods in feminist literature in relation to motherhood. According to Snitow (1992), in the first period (1963–1974) feminist scholars questioned the dominant idea

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[3] Essentialists believe that there are certain inherent attributes for every entity, such as men and women. According to Delamter and Hyde (1998), modern essentialism believes that "certain phenomena are natural, inevitable, universal, and biologically determined" (p. 10).

of being a mother as an integral part of a woman's life. The first period of feminist literature was primarily focused on women against the patriarchy, without considering women's issues in different contexts such as family; consequently, feminist literature failed to explore women's issues within a family and women's experiences of mothering (Snitow, 1992). The literature in the second period (1975–1979) was more focused on motherhood (Snitow, 1992). In this second period, Snitow (1992) argues that although feminist scholars attempted to separate the notion of womanhood from motherhood, they didn't discuss a woman's choice not to be a mother. Overlooking the choice of women to be childfree can imply the impact of essentialism in conceptualising motherhood in the second period. The third period started in 1980. Specifically, Ruddick's (1980) Maternal thinking was described by Snitow (1992) as an important feminist publication on mothering in this period. Ruddick (1980) challenged the way women's reproductive capacities have historically deemed motherhood as an essential and natural activity.

Contrary to the essentialist approach, many feminist scholars argue that historical, cultural and social factors play a key role in constructing the notion of mothering (Collins, 1996; Stack & Burton, 1993).

Earlier studies shed light on the way cultural and social constructions shape the notion of motherhood (Arendell, 2000; Baber & Allen, 1992; Hays, 1996; Thompson & Walker, 1989). These studies consider that motherhood is constructed within social interactions and based on traditional gendered relationships (Cowdery & Knudson-Martin, 2005; Hays, 1996; Kretchmar & Jacobvitz, 2002).

Sapiro (1986) notes that biological capacities do not lead to discrimination against women, but unequal social structures that are shaped by male privilege result in women's oppression:

Feminists argue that in most known societies this structure has granted women lower status and value, more limited access to valuable resources, and less autonomy and opportunity to make choices over their lives than it has granted men. Feminists further believe that although this gender-based world may be organized around biological facts such as the exclusive capacity of men to create sperm and the exclusive capacity of women to bear children, gender inequality is due to the social construction of human experience, which means that it should be possible to eradicate it. (p. 441)

Bassin and Kaplan (1996) claim that mothers were traditionally assumed to care for their family without considering their own needs and wants. Baber and Allen (1992) consider that the structure of the nuclear family in the modern era has shifted to the structure of diverse families in the postmodern era. Consequently, the historical construction of mothering that was shaped within a nuclear family had to be reconstructed. A nuclear family that consisted of a mother, a father and dependent children (Uzoka, 1979) was traditionally constructed on a gendered set of relationships; thus, a mother's role was to nurture children and a father's role was to work and earn money to maintain a family (Baber & Allen, 1992). In contrast to the nuclear family, in diverse families such as a single-parent family or childless family, a woman/ mother does not stay at home full-time to raise children, but she works to support her family (Gerson, 1983).

Earlier studies highlight the way the historical and social construction of motherhood is linked to the stereotype of a good mother (Chodorow, 1978; Dally, 1983; Hays, 1996). According to Johnston and Swanson (2006), a 'good mother' traditionally refers to being "full-time, at-home, white, middle-class, and entirely fulfilled through domestic aspirations" (p. 509). More recently, Kaspar and Kroese (2017) claim that the concept of a good mother comes from society, and is reproduced via the media, healthcare professionals, parenting manuals, magazines, newspapers and the internet.

Several scholars consider that the social construction of a good mother influences the experience of mothering (Frederick, 2017; Kerrick & Henry, 2017; Mays, 2006). Furthermore, various feminist theorists have critiqued the social construction of motherhood and highlighted the traces of perfectionism in the conceptualisation of motherhood (Hays, 1996; McMahon, 1995). The impact of perfectionism on the social construction of motherhood leads to accepting ideal standards as the true way of mothering. These standards define mothering as a full-time role for women to care for their family (Arendell, 2000; Hays, 1996; Lappeteläinen et al., 2018; Tardy, 2000).

Hays (1996) introduces the term 'intensive mothering,' which refers to mothering that is "centered, expert-guided, emotionally absorbing, labor-intensive, and financially expensive" (p. 8). Skinner (2013) considers that the stereotype of an intensive mother is the way that the majority of Western societies perceive mothering.

Similar to Hays (1996), Douglas and Michaels (2005) identify the idealism in shaping the construction of motherhood. Douglas and Michaels (2005) consider that the 'new momism' took root from the ideal of 'intensive mothering' in the late 20th century. According to Douglas and Michaels (2005), the 'new momism' is a set of ideals, norms, and practices, most frequently and powerfully represented in the media as a woman who loves all the moments of her mothering without showing her exhaustion.

Douglas and Michaels (2005) argue that while the new momism seems to be aligned with feminist aspiration it is in fact in contradiction to feminism. On the surface, mothers have control of their decisions: they can choose to work, be financially independent and follow their own dreams. But, in fact, the new momism strengthens the idea that a real woman is a mother who sacrificially cares for her child.

According to Choi et al. (2005), the experience of mothering consists of a range of emotions such as happiness and

exhaustion; but, while the notion of mothering is tied to perfectionism, mothers will hide the difficulties they experience in order to be considered a perfect mother. They may pretend to enjoy being a perfect mother, but in fact they reinforce the standards of being a perfect mother that are not attainable for all mothers (Douglas & Michaels, 2005).

The impact of idealism and an essentialist approach to mothering and womanhood leads a mother to lose her identity as a woman (Boulton, 1983). This is because of the social construction that a 'complete woman' needs to be a mother.

Feminist scholars argue that mothering is not a natural identity for women (Choi et al., 2005; Tardy, 2000). Similarly, Glenn (2016) highlights the way an essentialist approach to gender roles and women's reproductive capacities impacts the way women perceive their womanhood. Thus, Glenn (2016) sheds light on the impact of the social construction of idealism on the way women perceive their mothering:

> Mothering and gender are closely intertwined: each is a constitutive element of the other. Social relations of gender are fundamentally (structured). Perhaps because the gendered allocation of mothering appears to flow inevitably from the division based on reproductive function, mothering – more than any other aspect of gender – has been subject to essentialist interpretation: seen as natural, universal, and unchanging. Indeed, for most of the twentieth century an idealized model of motherhood, derived from the situation of the white, American, middle class, has been projected as universal. (p. 3)

Similar to Glenn (2016), several feminist scholars emphasise that considering mothering as a natural identity lays a moral responsibility on women's shoulders, which leads to the mainstreaming of the social construction of intensive mothering (Kerrick & Henry, 2017; Miller, 2007; Tardy, 2000). "In the history of philosophy, the nature attributed to women has been assumed to be inferior to the nature attributed to men; women have been characterized variously as passive, irrational, emotional, by nature bearers and care-takers of

children." (Stoljar, 1995, p. 262). Given that the notion of caring for a child is tied to the construction of motherhood as a natural identity, being a good mother is considered integral to a women's identity (Collett, 2005). "While social identities are inherently defined by roles and relationships, the identity of mother is distinctive. Being someone's mother is not enough. A mother's success is measured by her child's life and achievement" (Collett, 2005, p. 329). Arendell (2000) considers also that "definitions of mothering share a theme: the social practices of nurturing and caring for dependent children. Mothering, thus, involves dynamic activity and always-evolving relationships" (p. 1192).

As opposed to the social construction of mothering that traditionally perceives a mother to be the primary caregiver in child raising, taking care of her family and housekeeping (Olsen & Clarke, 2003; Rose & Cohen, 2010; Bassin & Kaplan, 1996; Johnston & Swanson, 2006), a disabled mother is not always the primary caregiver in her family. Consequently, families of mothers with disabilities are considered 'up-side families' (Lappeteläinen et al., 2018).

Given that the stereotype of a perfect mother is not attainable for the majority of able-bodied mothers (Olsen & Clarke, 2003; Prilleltensky, 2003), the social construction of perfectionism in mothering can likely only impact negatively on the way disabled mothers perceive their mothering. Consequently, these mothers who could be perceived as imperfect mothers – attempt to construct their mothering through different means such as being a supermom or using self-sacrificing strategies in order to prove their mothering capability to society (Shpigelman, 2015; Thomas, 1997).

2.2 Disabled mothers

In contributing to a better understanding of the experience of disabled mothers, this section brings the worlds of mothering and disability together and reviews the literature on mothering and disability.

The number of women with disabilities who choose to have children has increased (Smeltzer, 2007). There are limited documented studies on the experiences of disabled mothers but most of the researchers identify that stereotypes and material environments have made mothering for disabled women more challenging (Guerin et al., 2017; Payne & McPherson, 2010; Prilleltensky, 2003; Thomas, 1997; Wołowicz-Ruszkowska, 2016).

Aotearoa New Zealand statistics show that women who experience disabilities have poorer health outcomes and lower education achievements than able-bodied women (Stats NZ, 2013). In a study of 415 women with physical disabilities in the US, exploring the stress women with disabilities experience, Hughes et al. (2005) found that women with physical disabilities experience higher levels of stress compared to able-bodied women. Mays (2006) identifies that disabled women experience a higher incidence of domestic violence (such as physical or verbal abuse) than able-bodied

women. According to Iezzoni et al. (2013), the rate of poverty is higher in the population of women with disabilities in America and they usually have less economic participation in comparison to able-bodied women.

According to the World Health Organization (2011), one in five women have some form of disability. In Aotearoa New Zealand, women of reproductive age (ages 15 to 44) represent 16% of the physically disabled population (Stats NZ, 2013).

Thomas (1997) highlights that as a result of prejudicial attitudes, disabled mothers are unconfident and anxious about their ability to fulfil the mothering role. According to the literature (Collins, 2000; Luker, 2005; Thomas, 1997), the social construction of a good mother has an extra impact on the experience of women in minority groups such as disabled mothers. Mothers with disabilities who cannot fit the social construction of a good mother are socially devalued (Mays, 2006).

Mothers from minority groups such as black, single, queer and disabled have historically and socially been labelled as bad mothers (Collins, 2000; Hays, 1996; Luker, 2005). The social construction of 'bad' mothers refers to mothers who are socially excluded from the stereotype of a good mother and do not fit the mould of 'normal' mothers (Arendell, 2000; Frederick, 2017; Malacrida, 2007; Mays, 2006). The marginal position of disabled mothers highlights the impact of social constructions such as the stereotype of a good mother and the ideal of intensive mothering on their mothering experiences. Studies highlight how ideal standards of mothering can lead disabled mothers to consider themselves as incapable mothers. This is because disabled mothers could perceive themselves as far from the standard of a normal mother in society (Frederick, 2017; Malacrida, 2007; Prilleltensky, 2003; Shpigelman, 2015).

According to Daniels (2019), the normative approach to mothering privileges able-bodied mothers without considering human differences, and is based on the assumption that able bodies and their needs are appraised as normal in society. This approach to disability puts mothers with disabilities under the shadow of able-bodied mothers (Daniels, 2019). This is because ableism applies a normative lens to people's differences and thus considers disabled people as a separate group (Daniels, 2019). According to Campbell (2014):

> Ableism is deeply seeded at the level of epistemological systems of life, personhood and liveability. Ableism is not just a matter of ignorance or negative attitudes towards disabled people; it is a trajectory of perfection, a deep way of thinking about bodies, wholeness and permeability. (p. 80)

Daniels (2019) argues that the construction of motherhood has been impacted by ableist standards; thus, a real mother is socially constructed as an able-bodied mother who meets the ableist standards.

Clímaco (2020) considers the construction of motherhood from the intersectional lens of feminism and disability studies, and notes that the binary way of viewing motherhood leads to categorising women as normal or abnormal mothers. According to Clímaco the normative approach to mothering results in considering a disabled mother as a deviate mother. Consequently, the normative approach to mothering with disabilities leads to the oppression and discrimination of disabled mothers by devaluing them as abnormal mothers.

Daniels (2019) criticises the ideological approach to motherhood and the 'ideal mother' that is based on the construction of ableism. From Green's (2015) perspective the idea of a 'good mother' is the result of social construction and a patriarchal system that hinges on the stereotype of an extraordinary able-bodied woman (Daniels, 2019). Lewis (2002) considers that it is impossible for any woman to be a stereotypical perfect mother, even in the most privileged situation. Thus, Lewis (2002) considers that mothers who are not able to perform this stereotypical mothering will be stigmatised as unnatural and deviant mothers. Given that the ideal mother is the construction of a normative approach to femininity and motherhood (Malacrida, 2007), disabled mothers may not be considered 'real mothers.'

Disabled women have historically been assumed to be dependent, asexual and incapable; consequently, they have been stigmatised as incapable mothers (Daniels, 2019; Fritsch, 2017; Malacrida, 2007; Nosek, Howland et al., 2001; Parchomiuk, 2014).Traditionally, disabled women have been discouraged from becoming mothers and seen as incapable of looking after their children by society (Prilleltensky, 2003).

Previous studies show that the multiple barriers that disabled women confront in relation to their healthcare expose the women to stressful experiences. For instance, according to earlier studies, disabled mothers face various barriers during pregnancy and childbirth, such as insufficient healthcare support and inaccessible buildings (Akobirshoev et al., 2017;

Frederick, 2017; Iezzoni et al., 2017; Long-Bellil et al., 2017; Mitra et al., 2017; Smeltzer et al., 2017; Wint et al., 2016). Furthermore, healthcare providers and social workers have insufficient information on how to support disabled mothers during pregnancy and childbirth (Wint et al., 2016).

According to Garland-Thomson (2005), feminist disability theory challenges traditional ideas on disabled women and shows how social arrangements constrain their life choices. She argues that people are different from each other and these diversities may put them at the risk of discrimination. Consequently, people who are known as 'different' experience undesirable attitudes (Thompson, 2016). Garland-Thomson (2006), by refusing the normative approach to humans, considers disability as an individual difference. She argues that disability involves the interplay between bodies and material environments. From Garland-Thomson's (2006) perspective, disability is a social construction that shapes our experience of bodies.

Shpigelman (2015) considers independence, identity and social stigmas as the three main issues for disabled. Garland-Thomson (2011) challenges the ideal of independence, arguing that since humans experience various degrees of difficulty throughout their lives, everyone experiences dependency. Malacrida (2007) considers that while a mother who takes care of her child independently is known as a good mother in Western culture, this stereotyped mothering is not attainable for all women. Shpigelman (2015) mentions that mothers with disabilities have to overcome the negative stigmas regarding their motherhood and gain their mothering identity.

Disabled mothers have to conquer a wide range of obstacles such as negative stereotypes, inappropriate equipment, and financial and social issues (Kaiser et al., 2012). For instance, Schopp et al. (2002) identifies various attitudinal, environmental, economic and informational barriers to disabled women receiving health services.

In another study in Aotearoa New Zealand, the analysis of the experiences of women with MS during pregnancy and motherhood highlights the effects of the stereotypical expectation of being a 'good mother' for these women. While overcoming physical limitations and conserving energy were major concerns for mothers with MS, they expressed anxiety regarding their ability to demonstrate that they were capable of the role of mothering (Payne & McPherson, 2010). Although disabled mothers face various limitations in the material environment, the stereotypes regarding mothering can become more limiting than physical barriers. This is because, in this disabling environment, mothers with disabilities encounter many difficulties in having society accept them as capable mothers (Fitzmaurice, 2002; Grue & Lærum, 2002).

Disabled mothers have to overcome various physical and social barriers in society (Frederick, 2017). Fritsch (2017) reveals the various social barriers that parents with disabilities face, claiming that an inclusive approach to disability can diminish the effect of a normative view on the experience of mothering with disabilities.

There is limited data on the strategies that mothers with physical disabilities apply to help facilitate their mothering. Literature reveals the lack of systematic support for disabled mothers (Powell et al., 2019). According to Powell et al. (2019), there is a need to improve the support and products to meet the needs of mothers with physical disabilities. Similarly, Mitra et al. (2017) highlight that there is a lack of adaptive products and useful information for disabled parents. Consequently, parents are required to apply their own adaptive strategies in order to address their needs, such as modifying baby-related products (e.g., bed and cot) and making their home accessible. According to Wint et al. (2016), night care, bathing and carrying the baby are the most difficult tasks for women with physical disabilities.

The impact of factors such as social exclusion and discrimination, the lack of adaptive devices and the physical

environment make the experience of mothering more challenging for disabled mothers (Malacrida, 2007). The existing literature identifies that in Aotearoa New Zealand there is insufficient support for mothers' physical needs, including adaptive equipment for changing nappies, breastfeeding and bathing (Payne & McPherson, 2010).

The relevant literature regarding the experiences of motherhood with SCI are limited. Alexander et al. (2001) investigated the challenges of outdoor and indoor activities for mothers with SCI. They identified that outdoor activities, such as taking a child to a playground or restaurant, were difficult tasks for mothers. In addition, bathing a child and getting up at night to attend to a child were identified as the most significant challenges they faced in the domain of indoor activities. Kaiser et al. (2012) explored the role of adaptive products for parents with SCI. According to their findings, there is a strong need to develop assistive equipment for parents with SCI (e.g., changing tables, strollers, car seats,

bathtubs and cribs). Reid et al. (2003) investigated the experiences of women who use wheelchairs and highlighted the decisive role of physical barriers in restricting women in homemaking roles such as doing laundry, changing their baby's diapers, cleaning their child's bedroom and washing dishes.

Although the existing literature provides useful insights regarding mothering with SCI, it does not capture specific knowledge that would frame and illuminate the complex interplay between mothers with SCI and child-caring products. Past studies have identified the various challenges that mothers with SCI have to deal with. By considering the importance of such literature in informing this research, it has also demonstrated that there is a specific knowledge gap in the existing studies regarding the experience of mothering with SCI as follows:

1.   This literature has not explored the interplay of mothering with SCI and child-caring products through a co-design process.

2.   Most of the literature considers the difficulties and barriers of mothering in the domain of disability rather than design practice.

3.   A further gap in the literature is the failure to explore the role of product design to construct more meaningful mothering experiences for mothers with SCI.

2.3 Product design for disabled users

This section begins with an introduction to the marginal position of women as designers and users in product design practice. Then it reviews the existing literature on how product design practice has met users' needs. This is followed by a discussion on design attempts to address the needs of disabled users.

Male designers have traditionally dominated the design discipline. Buckley (1986) describes the various roles of women as designer, scholar, historian and user in the design area, and considers that patriarchy leads to limiting women's participation in society in general and the design area in particular. Parker and Pollock (2020) highlight that "because of the economic, social, and ideological effects of sexual difference in a Western, patriarchal culture, women have spoken and acted from a different place within that society and culture" (p. 53). According to Buckley (1986), patriarchy and traditional constructions devalue women's position both as designer and user. These patriarchal constructions lead society to perceive women as less capable than men to participate in physical and intellectual sectors of design such as product design. Historically, women were involved in the areas of design that align with female stereotypes and their traditional

roles both as designer and user (Anscombe, 1984; Attfield, 1989; Buckley, 1986).

Studies show that female designers have more commonly practised in domestic and decorative fields, such as interior design, textiles and jewellery design. This may result from the traditional role of women in the non-industrial sphere (Anscombe, 1984; Attfield, 1989; Buckley, 1986). Thus, industrial fields of design still remain male dominated (Allen, 2013; Bruce & Lewis, 1990; Reid et al., 2003).

The literature also identifies a similar marginal position of women in the design sphere as users (Allen, 2013; Reid et al., 2003). Previous studies have identified products that were designed for women, by men, and had failed to successfully meet the needs of women (Forty, 1986). This is because, the essentialist approach to gender roles results in viewing a woman only as a housewife and caregiver to her family (Parker & Pollock, 2020). Hence, women are targeted by male designers as the sole users of home appliances. For instance,

women have the main roles in advertisements for household appliances whereas they may be seen rarely in advertisements for cars (Parker & Pollock, 2020).

Decades later, there are still a number of attempts to design for women, but these appear to draw on stereotypical gendered notions of what women's needs are (Forty, 1986; Parker & Pollock, 2020). For instance, in 2016, the collaboration between manufacturer SEAT and a lifestyle magazine resulted in the Mii electric car. This small car has safety assistance for women users. It also offers decorative features to personalise the exterior and interior, and matching keys. The car manufacturer mentioned that the Mii makes driving easier for 'women'. They also considered that the car includes 'jewelled, bi-colour alloy wheels' which was considered as a 'surprise sparkle' for women. The car was available in aubergine and Candy White colour with purple Alcantara seats. Despite the novelty of the Mii, it would seem that women have far greater

needs, which could be addressed through design, than their car's appearance and decorative features.

As Buckley (1986) considers, while women's expectations, needs and desires as both designers and users are constructed within a male-dominant culture, the codes of design (as used by designers) are also produced within the dominant paradigm. They are, therefore, dominant codes. Similar to female users, disabled users are another minority group who have been marginalised through product design practice. In the area of product design for disabled users, earlier studies also highlight the impact of a dominant approach (i.e. able-bodied users) on product design for disabled users (Hamraie, 2016; Imrie, 2012).

However, product design has the potential to better address the needs of minorities such as disabled users. Previous studies highlight that a product design approach to users and their needs has changed over time. This is mainly due to the fact that users' position within product design has changed

noticeably over the years. While in the early 20th century product design was mainly focused on function, it has gradually leaned more toward better identifying users' needs and, eventually, centralising users in design.

Functionalism in design, according to Bannon and Ehn (2012), was initiated in the 1930s in Scandinavian countries; however, it was further developed in Europe after World War II. Buchanan (2007) categorised design research in the 20th century into three groups: the dialectic, scientific and inquiry approaches. According to Buchanan (2007), the dialectic approach focused on social and cultural constructions through design research, the scientific approach mainly explored technical issues and mechanisms through the design process, and the inquiry approach referred to designers' creativity. Dixon (2019) highlights that design research has shifted from the scientific approach to design inquiry in recent years.

According to Ehn (1993), "the origin of design is in involved practical use and understanding, not detached reflection, and

design is seen as an interaction between understanding and creativity" (p. 62). However, from Buchanan's perspective (2001), "design offers a way of thinking about the world that is significant for addressing many of the problems that human beings face in contemporary culture" (p. 38). From Kimbell's viewpoint (2011), Buchanan (2001) considers designers as liberal artists who reframe the way of defining problems and exploring solutions.

There are different definitions for the way designers think and apply methods to explore creative design solutions. From the 1960s, as a result of the expansion of technology and its impact on human lives, scholars began to structure the design process more explicitly (Beckman & Barry, 2007). Cross (1982) discusses the "designerly way of knowing".[4] Bunchman (1992) describes many design problems as "wicked problems."[5] Therefore, designers aim to "produce solutions" to these problems. While finding innovative design solutions to address users' needs is one of the main aims of designers, it is not always possible to identify any creative idea or product-related issue by simply asking individual users to talk about their experiences, as some experiences are too complex to be assessed fully in this way.

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[4] "There are five aspects of designerly ways of knowing:

Designers tackle 'ill-defined' problems. Their mode of problem-solving is 'solution-focused'. Their mode of thinking is 'constructive'. They use 'codes' that translate abstract requirements into concrete objects. They use these codes to both 'read' and 'write' in 'object languages'" (Cross, 1982, p. 11).

[5] The term "wicked problem" refers to "a class of social system problems which are ill-formulated, where the information is confusing, where there are many clients and decision makers with conflicting values, and where the ramifications in the whole system are thoroughly confusing" (Churchman, 1967, p. 37).

Gradually, designers have recognised the value of having more insight into users' needs and wants; thus, various methods have been developed for this purpose. For example, empathic design aims to design products by understanding users' needs and feeling through empathy, in a user-centred design approach (McDonagh-Philp & Lebbon, 2000). Empathy in design refers to the "ability to 'be' as the other, while remaining a whole self, or the ability to stand in someone else's place while standing in your own" (Nelson & Stolterman, 2012, p. 54).Through empathic research, designers focus on finding problems rather than seeking design solutions (Thomas & McDonagh, 2013).

The use of cultural probes (Gaver et al., 1999) is another method that aims to help designers better understand users' values, culture and thoughts by eliciting inspirational responses from users through small packages such as a map, postcard, camera or diary. The probes (i.e., packages, images and objects) are applied to increase participants' engagement in the design process (Halpern et al., 2013). Participants are invited to document and reflect their experiences through the use of such probes.

The PrEmo method (Desmet, 2002) measures the emotional impact of products on user experiences through 14 emotional cartoon characters. There are seven positive and seven negative cartoon reactions (i.e., face, voice and body language of the cartoon character) and users are invited to choose cartoon reactions to express their feelings and emotions towards products, services and concepts.

Kansei engineering (Nagamachi & Lokman, 2016) is a methodology that aims to translate user emotions to physical properties through semantic differential scales. The semantic differential scale (Osgood et al., 1975) is a rating scale used to measure the participants' attitudes and responses towards objects, words and concepts. In Kansei engineering, the semantic differential scale is applied to match users' feelings to design properties (Yodwangjai & Pimapunsri, 2011).

The above methods have brought theoretical and methodological richness to the field of user experience design.

These methods are only examples of user-centred design methods which focus on users at the centre of product design and development to better understand users' needs and dreams. It should be noted that participatory design and co-design are further discussed in Chapter 4.

According to Bannon and Ehn (2012), user-centred design stemmed from participatory design. Bardzell (2018) asserts that participatory design aims to communicate with users in a democratic way. In doing so, design projects must be defined by users' participation. From Bardzell's perspective (2018), this strategy reduces the risk of overlooking users' needs in the design process.

Simonsen and Robertson (2012) argue that participatory design is socially constructed through the interaction between users and designers within a collaborative process of concept generation, idea development and their communications. Winschiers-Theophilus et al. (2010) highlight that participatory design can be influenced by social and cultural constructions. This is because the social and cultural differences between designers and users can lead to unmet needs of users through design. From the perspective of Winschiers-Theophilus et al. (2010), considering users' diversity can play a significant role in paving the way to addressing the users' needs more effectively.

The potential of users' participation to contribute to innovative ideas that meet their needs effectively has been acknowledged in earlier studies (e.g., Lengnick-Hall, 1996; Von Hippel, 1988). Giacomin (2014) suggests that current human-centred design emphasises users' participation by applying "techniques which communicate, interact, empathize and

stimulate the people involved, obtaining an understanding of their needs, desires and experiences which often transcends that which the people themselves actually realized" (p. 610). Consequently, human-centred design differs from more traditional design processes, which focuses on a designer's creativity, materials and technology to solve users' problems.

Giacomin (2014) considers that, over time, the design paradigm has shifted from focusing on ergonomics and functionality to human-centred design that aims to construct meaningful user experiences. Giacomin (2014) states that, recently, well-known companies not only address users' physical and functional needs but also focus on their emotional needs, to create meaningful experiences for their users through products. Giacomin (2014) mentions prominent companies including Alessi, Armani, Apple, Facebook, Ferrari, Google, IKEA, Nokia, Phillips and Virgin as examples of companies that create new meanings for their products by addressing users' emotional needs.

Given that users' participation can have a significant role in product design and development (Nambisan & Nambisan, 2008), product designers employ various means to engage potential users through the design process. According to Nambisan and Nambisan (2008), companies use creative strategies to engage users through the design process. For instance, Volvo has sought users' participation through a virtual product concept try-out. Nambisan and Nambisan (2008) highlight that the virtual product test was not only helpful to engage users through the design process, but it also sped up the product development process.

Steen (2013) considers co-design as one of the innovative design processes that stem from participatory design. According to Steen (2013), the participation of users and designers leads to concept generation and development through a collaborative process of sharing ideas. Steen (2013) highlights that a co-design approach to products typically differs from a science and engineering approach. This is

because science aims to describe situations and discover facts, and engineering focuses on finding the best solution for a problem by using facts. Nonetheless, design intends to explore new opportunities by considering facts and values. Both participatory design and co-design are further explained in Chapter 4.

In identifying the needs of users, there have also been attempts made to consider the needs of disabled users through product design practice. Examples of these attempts are universal design (Mace, 1998; Steinfeld & Maisel, 2012) and inclusive design (Coleman & Lebbon, 1999; Imrie & Hall, 2001). These attempts aimed to meet the needs of a wide range of people, regardless of age, gender, size or their physical differences, through design.

Clarkson and Coleman (2015) state that for users, design can be disabling or enabling, depending on how it is used to people. More specifically, disabled users can be considered as 'others' or as 'us'. Clarkson and Coleman (2015) argue that the shift from viewing disabled people with disabilities as 'others' to 'us' would more likely lead to their inclusion through design. Thus, this shift would help design to play an enabling role for disabled people rather than be a disabling factor. Inclusive design aims to better address the needs of minority groups based on the following premises (Clarkson & Coleman, 2015, p. 235):

1.   There is such considerable diversity in mental and physical capability both across the population and over the length of the life-course that the association of 'normality' with 'able-bodiedness' is neither accurate nor acceptable.

2.   Disability arises from interactions with the surrounding environment that are amenable to design and structural interventions, and not inherently from capability levels, health status, or associated degrees of impairment.

Fletcher et al. (2013) highlight that the terms universal design and inclusive design can be used interchangeably. This is because both universal design and inclusive design aim to include a wide range of potential users by considering people's diversities, such as physical abilities and age (Fletcher et al., 2013). According to Fletcher et al. (2013), the universal design committee of the Industrial Design Society of America (IDSA) commenced in 1993 with nine members. However, after a short period, the number of members grew from nine to over 600, which acknowledges the interest of the design society in including people with disabilities through design.

The universal design principles were developed by a group from the universal design section of IDSA under the supervision of James L. Mueller, the section leader, and Molly Story, the co-chair of the universal design section (Fletcher, 2015; Fletcher et al., 2013). According to Mace (1985), universal design refers to "a way of designing a building or facility, at little or no extra cost, so that it is both attractive and functional for all people, disabled or not" (p. 147). Mace's emphasis on 'design for all' highlights the inclusive approach of universal design toward the diversity of humans rather than applying a normative lens to people's bodies.

Story (2001) highlights that initially there were no clear universal design criteria. According to Story (2001), research done by the Center for Universal Design in the US during 1994 to 1997 identified seven principles of universal design as follows:

Principle 1: Equitable use. The design is useful and marketable to people with diverse abilities (p. 4.6).

Principle 2: Flexibility in use. The design accommodates a wide range of individual preferences and abilities (p. 4.6).

Principle 3: Simple and intuitive use. Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level (p. 4.6).

Principle 4: Perceptible information. The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities (p. 4.9).

Principle 5: Tolerance for error. The design minimizes hazards and the adverse consequences of accidental or unintended actions (p. 4.9).

Principle 6: Low physical effort. The design can be used efficiently and comfortably and with a minimum of fatigue (p. 4.9).

Principle 7: Size and space for approach and use. Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility (p. 4.11).

These principles aimed to clarify universal design guidelines, and thus provide users and designers with a better understanding of usability through design (Story, 2001; Story, Mueller, & Mace, 1998).

The application of the universal design principles has aimed to include people with a wider range of physical abilities. Story (2001) highlights the impact of universal design to facilitate more accessible public transport, including trains and buses, for people who use wheelchairs and walking aids. One example could be a mechanical or foldable ramp to facilitate the process of getting on and off trains and buses (see Figure 2.1).

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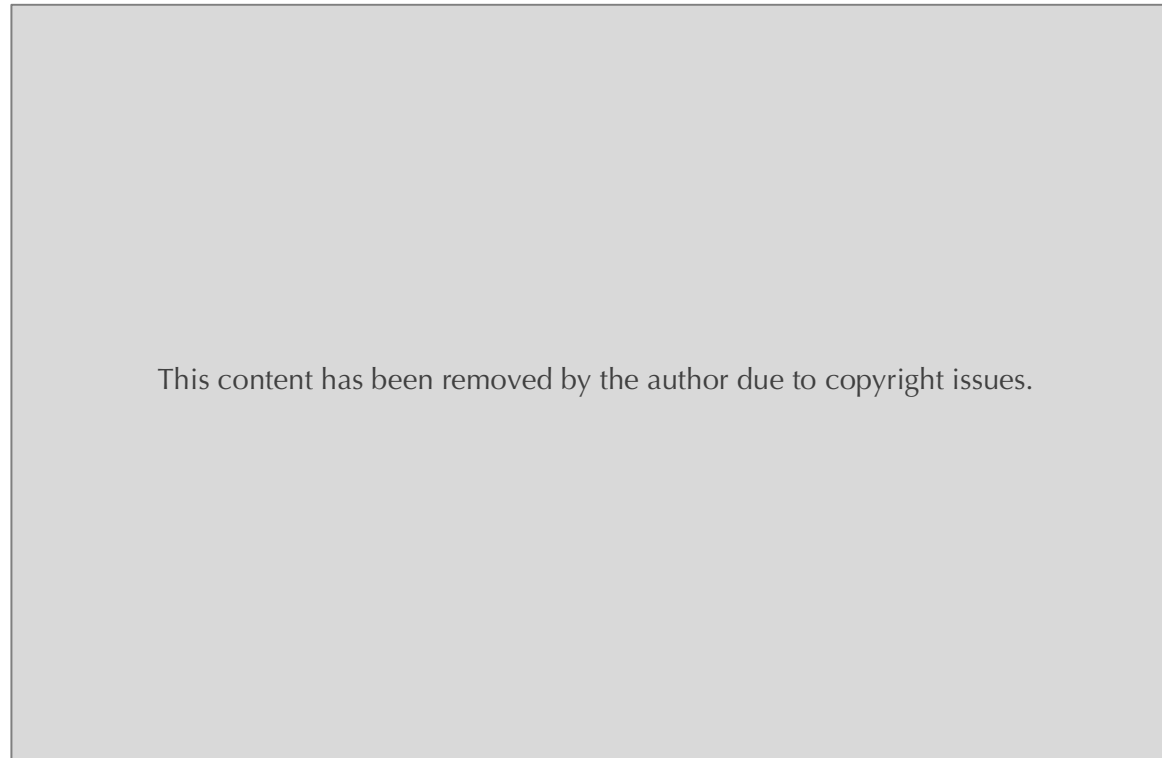
Figure 2.1. A sample of a universal design product, a mechanical ramp to facilitate the process of getting on and off a bus (Story, 2001, p. 19.5).

Given that the aim of universal design is to broaden the range of users, product designers apply different strategies to address the needs of those users. For instance, Figure 2.2 shows an adjustable medical examination table that was designed to include the different variations of users' bodies in order to meet the needs of people (i.e. patients and health professionals) by adjusting the height of the table (Story, 2001).

The adjustable height of the examination table aims to provide individuals with different physical abilities with more convenient positions to use it in by adjusting to their desired height.

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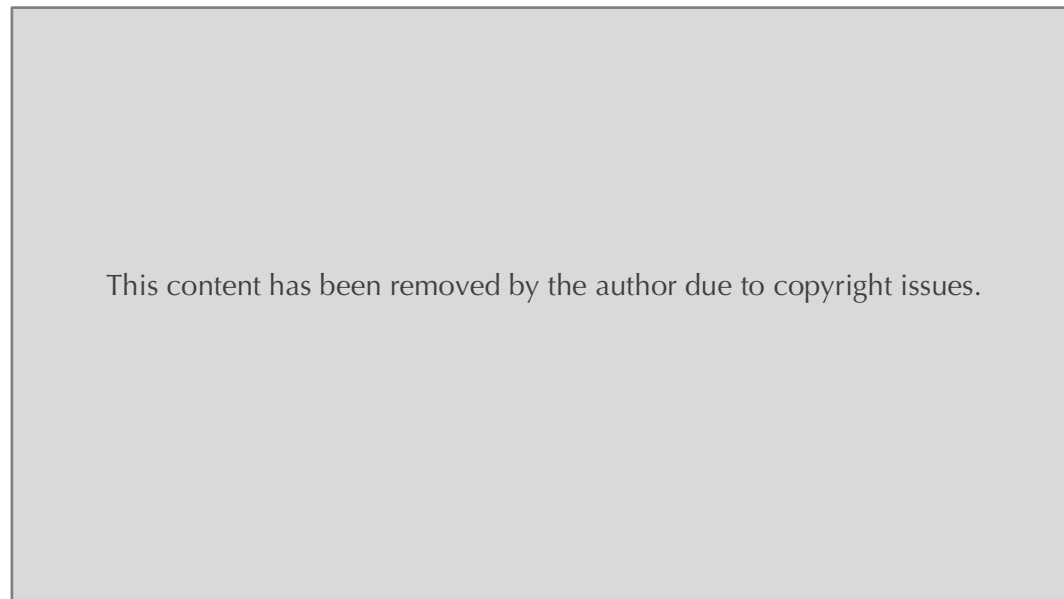
Figure 2.2. A sample of a universal design product, a height-adjustable examination table that is designed to address the needs of user with different physical abilities (Story, 2001, p. 4.8).

Story (2001) highlights the importance of connections through networks between designers and disabled users to reinforce universal design as a human-centred design approach. This is because, these connections would be an opportunity for designers and users to exchange information and experiences on universal design to better understand the needs of users. For instance, Story (2001) mentions the interactive product exhibition *Universal Design: Designing Our Future*, held in several cities in Germany between 2008 and 2010, showcasing over 50 household products from various German companies. These products were designed to meet the needs of a wide range of people with different physical needs. In this exhibition, people were encouraged to try out products through an interactive screen and share their feedback with designers. These included household products and appliances, such as a washing machine designed by Bosch and Siemens (Figure 2.3). The control panel of this washing machine was designed to be on the front top of the machine. The aim of this strategy was to make the process of loading and unloading clothes easier for users by placing the drum door at a higher height and a more accessible position for opening. The program setting of this washing machine works with a rotating dial and a line of buttons on the panel (Story, 2001).

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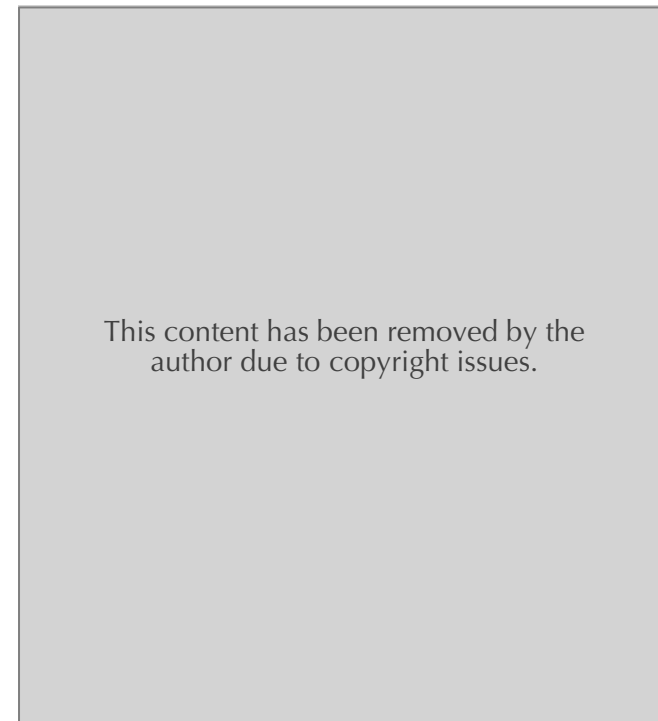
Figure 2.3. A sample of a universal design product, a washing machine by Bosch and Siemens that is designed to facilitate the process of loading and unloading clothes for users (Story, 2001, p. 13.4).

OXO company is another example of product design attempt to include all people regardless of their physical ability (i.e. users' strength and dexterity) in using their products. OXO and its 'Good Grips' line of kitchen tools aim to provide convenient grips for users with different physical abilities in grip (Coleman et al., 2016). The handle used in the design of 'Good Grips' kitchen utensils is thicker than the ordinary ones, making them more convenient to use in particular for people with dexterity difficulties.

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Figure 2.4. Samples of OXO 'Good Grips' kitchen utensil set, Source: https://www.oxo.com/categories/cooking-and-baking/tools-and-gadgets/tool-sets/oxo-good-grips-18-piece-kitchen-utensil-set.html.

Desmet and Dijkhuis (2003) highlight the importance of pleasant emotions in the design of a wheelchair for children. According to their findings, the integration of emotional theories and users' participation through the design process can be useful to create pleasant emotions for wheelchair users. The result of their design projects, which was carried out among 8 children aged 7-12 years old in Netherland, led to a concept of a wheelchair for children which specifically addressed the emotional and functional features of a wheelchair. This concept with its sporty appearance had three wheels to provide users with a better ability to manoeuvre in indoor and outdoor places. To do so, large tube diameter and treaded tires were designed to facilitate the handling of a wheelchair (Figure 2.5). Their findings indicated that a wheelchair designed for children could create fun emotions.

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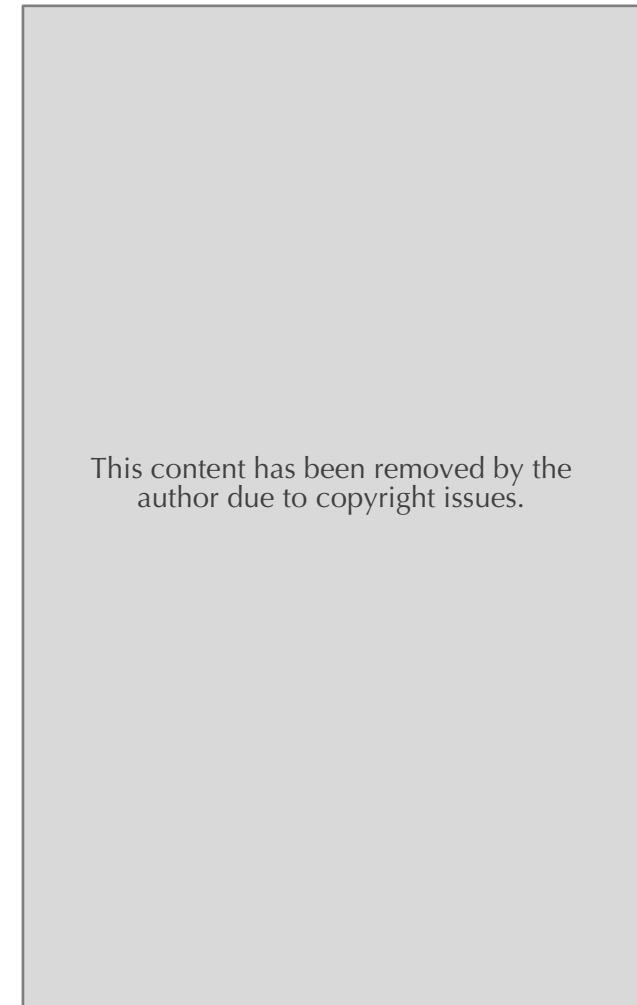
Figure 2.5. Final concept of a wheelchair design for children (Desmet & Dijkhuis, 2003, p. 26).

A new perspective toward product design for disabled users is offered by Pullin (2009), in which he reframes the way of viewing products for disabled users and how they could be used as fashionable products. Pullin (2009) uses the example of spectacles and states that while spectacles are similar to devices such as hearing aids and leg prostheses, nowadays eyewear is considered a fashion product and people who wear glasses are not stigmatised by society.

Pullin (2009) highlights the role of design in making assistive devices such as glasses into a fashion product. In addition, Pullin (2009) argues that assistive devices not only need to employ technical and engineering considerations to address physical needs of disabled users, but also the style of these products has to meet the aesthetic needs of the users. Pullin (2009) also mentions that, similar to the shift of spectacles to eyewear that is socially accepted, wheelchairs can also be designed with diverse styles for different occasions, with the aim to be socially perceived as a chairwear.

Although some design projects have attempted to meet the needs of disabled users, literature shows the failure of product design in applying a pluralistic approach within the design discipline. Hamraie (2013) criticises the epistemology of ignorance within design practice that leads to the exclusion of minority groups. Historically the dominant approach to 'normal' users impacts the way design has been used to address the needs of disabled people. Gibson (2014) highlights that the normative approach of design values people's independence, and thus attempts to maintain people's independence through the material environment such as products. Gibson (2014) challenges the notion of a person's static independence:

> Inherent in a problematization of independence is a questioning of some of the philosophical underpinnings of much of what gets done in the name of helping disabled people, whether it is through design, policy, clinical treatment, social services, education, or the like. Independence can be thought of

in many different ways that overlap and are often conflated: freedom, self-determination, sovereignty, self-sufficiency, living alone and control. But at its most fundamental, independence relates to the enlightenment notion of humans as fixed beings, composed of individuated minds which are encased in biological bodies. (p. 1329)

From Gibson's viewpoint (2014), independence is a temporal notion through the interaction between bodies and the environment.

Hamraie (2016) considers that initial attempts in accessible design hinged around the normative standards that were used in architecture. The normative approach in design was intensified by the impact of various factors, including the polio epidemic, World War II and injured returnee veterans. These factors led to an increased use in a medical approach to the human body and its function, which led to an accelerated application of normalcy in design. Consequently, the focus of design for disabled people was based on designing devices that addressed the needs of injured or disabled people in order to make them productive workers in society (Williamson, 2012). In doing so, the focus of design was mainly on diminishing the effect of injury rather than challenging the normative approach to the human body. As a result, the role of design was to assist individuals with disabilities to become 'normal' people (Serlin, 2004, p. 27).

While the rehabilitation experts used accessibility as a way to normalise the lives of disabled people and designers perceived accessibility as a barrier to limit their creative concepts, disability activists concentrated on the notion of accessibility as a strategy to include social participation of disabled people (Hamraie, 2016). Social disability activists placed emphasis "on disability as a cultural resource that should be valued and preserved through accessible built environments" (Hamraie, 2016, p. 8). However, recent critical disability scholars state that the social model of disability mainly concentrates on accessibility and physical environment design from a

functional perspective; thus, the lens of the social model is insufficient to probe the impact of ableism on the lives of people with disabilities (Hamraie, 2016).

According to Hamraie (2012), depending on the epistemic position, three themes are identified for universal and collaborative design research. The first *theme* is user-centred design, coined in the 1960s. This approach addresses human needs based on empirical knowledge, quantities and ergonomics. The second theme rests on design thinking and the designerly way of knowing and process. (Hamraie, 2012) called the third theme "normate template" (p. 5), in which the able human body is the basis of design. Hamraie (2012) claims that the normate template becomes a reference for architects and industrial designers and excludes human variation. Consequently, this approach results in neglecting the needs of minority groups (Garland-Thomson, 2011; Hamraie, 2012; Titchkosky, 2011).

Previous studies highlight that while universal design aims to include disabled (MacKay, 2006), it excludes individuals who do not meet its essentialist criteria (Graham, 2008). The essentialist criteria of universal design refer to its approach to the human body, which considers an able-bodied user as a normal reference and aims to broaden the range of able-bodied standards to people who do not fit normal standards. Hence, the standards remain, but are broadened; however, there are still many people who continue to be marginalised.

Imrie (2012) challenged the essentialist perspective of universal design, stating that it did not diminish the normative standards in the design discipline but simply broadened the criteria of design standards by including some disabled people (such as wheelchair users). However, universal design is insufficient to include all disabled users and some needs of users with disabilities fail to be addressed, as these users do not meet the universal design standards (Imrie, 2012). This is because, the essentialist lens of universal design has resulted

in designers overlooking the diverse ways in which bodies interact with objects and places. Gibson (2014) argues that using certain standards that are based on able-bodied people lead to exclusion of some users through universal design. Hamraie (2016) highlights the lack of cultural representation of disabled users in universal design. According to Hamraie (2016), the integration of critical theory disability and universal design would be beneficial to better address the needs of disabled users. From her perspective, the application of critical disability theory would pave the way to consider the impact of historical and social constructions on how universal design addresses the needs of disabled users; thus, to prevent the ableist approach through universal design.

Imrie (2012) considers that "UD cannot be universal unless it is embedded into the specificities of corporeality, and the differences that different bodies make in their everyday interactions with designed artefacts" (p. 880). This is because the universal design standards are shaped by the historical and social construction of "the norm of typical bodily forms" (Gibson, 2014, p. 1329). In other words, the way universal design responds to disabled users does not diminish the social construction of able-bodies as normal users, but it broadens the standards of the social construction of normal bodies. Consequently, applying normative standards through design mainstreams specific types of bodies as normal users rather than including body variations.

In summary, previous studies indicate the attempts product design has made to meet the needs of disabled users. According to the literature, while product design practice applies an able-bodied person as a design reference, therefore, even when strategies such as universal design are employed to include disabled people, users who do not conform to the reference standards continue to be marginalised in the field of design. This stresses the importance of rethinking the way of addressing the needs of disabled users through products design practice.

Conclusion:

The review of the literature reveals the social and environmental barriers faced by disabled mothers in society and the material environment. The literature review also highlights the way product design that addresses the needs of disabled users has been impacted by the normative approach to able-bodied people. This is because the dominant culture within design practice results in designing products and material environments that are fit largely for able-bodied people.

Given the limited attention given to research on the construction of meaningful experiences for mothers with SCI, and the potential for product design to better address the needs of disabled users (and create more meaningful experiences for them), it is important to further explore the construction of meaningful mothering experiences with SCI through the use of products.

Chapter 03. Methodology

"Knowledge consists of a series of structural/historical insights that will be transformed as time passes. Transformations occur when ignorance and misapprehensions give way to more informed insights by means of a dialectical interaction." (Guba & Lincoln, 1994, p. 113)

Introduction

The main aim of this chapter is to lay out the parameters within which the study was conducted, and describe the use of critical research, informed by theory. This chapter begins with an explanation of the research paradigm (section 3.1). Then, the research epistemology is discussed (section 3.2). The research theoretical approach that was employed as the research framework is presented in section 3.3. I applied feminist disability theoretical framework as a suitable complementary combination with my research methodology to explore different ways of looking and thinking about the experiences of mothers living with SCI.

Feminist disability theory stands against the women's objectification and attempts to destigmatize all women by respecting their diversity (Garland-Thomson, 2002, 2005). Given that the aim of this research was to explore the interplay between mothers with SCI and child-caring products in the home environment, I adopted a qualitative research approach to perform a deep exploration throughout the research process. As a qualitative researcher, I was interested in exploring how mothers with SCI construct meaningful mothering experiences through child-caring products.

This chapter establishes the relationship between the purpose of the inquiry and the chosen methodology. Participatory Action Research (PAR) has been chosen as the most appropriate overarching methodology to explore this topic (section 3.4). The trustworthiness of the research is discussed in section 3.5, followed by an examination of the ethical issues considered

for my study (section 3.6). Lastly, the conclusion is established in section 3.7.

3.1 Research paradigm

According to Guba & Lincoln (1994), a research paradigm "represents a worldview that defines, for its holder, the nature of the 'world', the individual's place in it, and the range of possible relationships to that world and its parts" (p. 107). Guba & Lincoln consider positivism, postpositivism, critical theory, and constructivism as research paradigms. This research applies critical theory as a research paradigm.

According Scotland (2012) the critical theory paradigm focuses on social issues and marginalisation. Additionally, critical studies tend to apply a qualitative research approach (Maroun, 2012). This is because, qualitative research aims to gain deep insight and understanding rather than making statistical generalisations (Creswell, 2007); thus, the qualitative approach provides a researcher with a better

understanding of the influence of social and historical factors in the research. In critical studies, participants and researchers are considered the research subjects exploring reality and reproducing knowledge through a dialectical process. (Guba & Lincoln, 1994; Scotland, 2012).

Guba & Lincoln (1994), consider three concepts related to research paradigm: ontology, epistemology and methodology. Ontology refers to the understanding of the nature of reality (Guba & Lincoln, 1994); how reality exists and what can be known about it. According to Guba & Lincoln, critical theory applies a historical realism ontology. Historical realism ontology refers to:

> A reality is assumed to be apprehendable that was once plastic, but that was, over time, shaped by a congeries of social, political, cultural, economic, ethnic, and gender factors, and then crystallized (reified) into a series of structures that are now (inappropriately) taken as "real," that is, natural and immutable. For all practical purposes the structures are "re*al," a virtual or historical reality*. (Guba & Lincoln, 1994, p. 110)

In this research, I applied critical theory paradigm to explore the construction of meaningful mothering experiences with SCI through child-caring products (Figure 3.1). In doing so, it is important to acknowledge that reality exists, but it has been shaped by social, historical, and gender factors that interact with each other to construct meaningful mothering experiences. This is because, while mothers with SCI may experience similar products and mothering activities, the meanings they construct of reality may be different. Consequently, as a critical theory researcher, it is important to acknowledge that reality exists but it is shaped by social, cultural and historical factors.

According to Harding (1987), epistemology is a "theory of knowledge" with focus on the "knower," a methodology is "a theory of how research is done or should proceed" (p. 3) and a method is "a technique for (or way of proceeding in) gathering evidence" (p. 2). In this way, feminism was applied as a research epistemology and Participatory Action Research (PAR) was used as the overarching methodology of this research. Thus, co-design and semi-structured interviews were applied as the main methods of the research (section 4.2).

Paradigm: Critical theory

Epistemology: Feminism

Theoritical framework: Feminist disability theory

Methodology: Participatory Action Research (PAR)
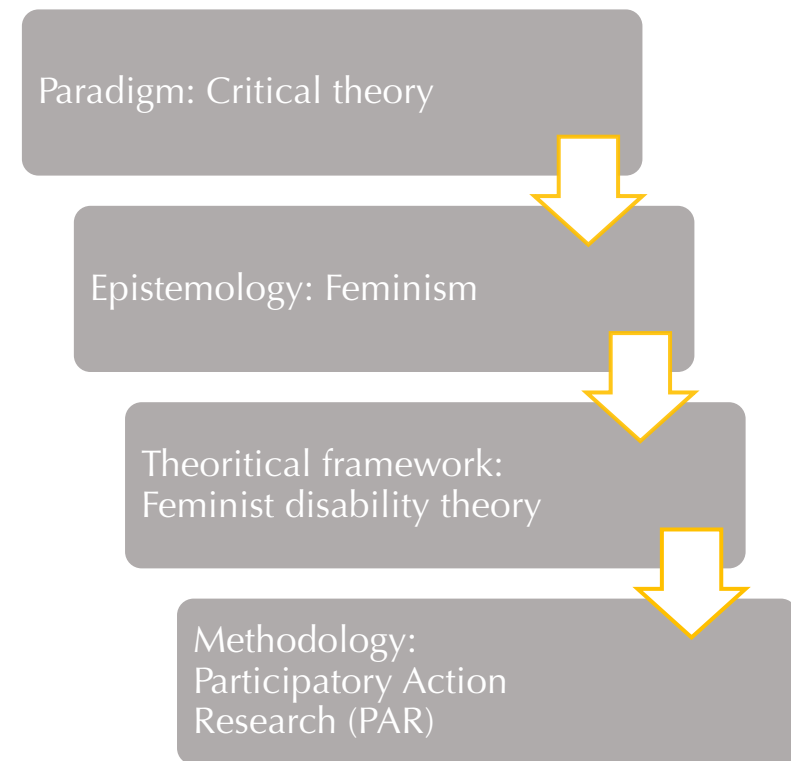
Figure 3.1. Research Paradigm

3.2 Research epistemology

Feminist studies apply a critical perspective to explore the impact of social, historical and gender factors on women's' experiences. According to Guba and Lincoln (1994), the critical paradigm aligns with my feminist epistemological position. Critical theory challenges unbalanced power relations in society and seeks to discover the impact of social, ethnic and gender interaction within society. Similarly, feminism challenges unbalanced gendered power relations within society and seeks a democratic society (Hesse-Biber, 2011). There are several different feminist theories. Despite their differences, all feminist theories critique the gender inequalities and aim to change these inequalities (Martin, 2003).

In general, feminist epistemology is focused on the influence of gender on conceptions of knowledge, thus it intends to change the male-dominant culture for women and minority groups (Anderson, 2004). Feminist research is shaped by feminist epistemology. According to Kumar (2014), feminist research differs from traditional research in three ways: the aim of the research, the methods, and the role of the researcher.

Numerous feminist scholars argue that male-dominant knowledge denies women's epistemic perspectives (e.g., Carr, 2003; Hesse-Biber, 2011; Narayan, 2010; Worell & Remer, 2002). Carr (2003) considers that feminist epistemology emphasises the significant role of gender in all analysis. Feminists believe that the entry of women into research generates new questions, theories and methods in academic disciplines (Hawkesworth, 1989; Hesse-Biber, 2007; Stanley & Wise, 1990). According to Hawkesworth (1989), the new way of recognising "knowing, knowers and known" creates new explorations at the centre of feminist epistemological discussions. Given that the main subject focus of feminist research is women, feminist researchers apply participatory approaches to explore women's experiences and perspectives (Kumar, 2014).

Literature highlights the significant role of the knower in feminist epistemology. Feminist philosophers challenge the dominant knowledge, which they argue is produced by dominant knowers (Nelson, 1993). Feminist scholars believe the social, cultural and political contexts influence the way of knowing and the production of knowledge (Hidayat, 2018). Code (1991), a feminist researcher and expert in feminist epistemology and politics of knowledge, argues in her book, *What Can She Know?*, that male knowers and men's way of knowing, influence the known. Consequently, the dominant epistemological position of men can result in women's marginalisation in knowledge production (Margonis, 2007).

In opposition to the dominant way of knowing, Hidayat (2018) claims that feminist scholars are open to a pluralistic way of knowing. Many feminist scholars believe that a feminist epistemic perspective opens space for women as knowers to diminish gender inequality by providing an opportunity to participate in the process of knowledge production (Code,

1991; Harding, 1987; Phelan, 2017). From a feminist perspective, the knower has a vital role to contribute to knowledge (Locher & Prügl, 2001). Considering the key role of epistemological approaches in various research (Poulsen & Thøgersen, 2011), a feminist epistemological position can assist researchers and designers to better explore the construction of meaningful experiences for women.

According to Hesse-Biber (2007), feminist scholars attempt to better understand how realities are constructed for women; thus, to explore the influence of these constructed realities on women's subjective experiences. In doing so, most contemporary feminist studies attempt to give a voice to aspects of women's lives which have often been neglected. Hesse-Biber (2007) identifies feminism as seeking women-centred unity and social change by uncovering hidden knowledge which may be contained within women's experiences.

More specifically, in this research, I applied a feminist postmodernism epistemic position, on account of the fact that feminist postmodernism argues knowledge is located socially and historically (Leavy, 2007). It challenges modernism's notion of idealism, ultimate universal principles and certain truth; consequently, feminist postmodernism emphasises personal narratives to show intersectional feminism (Hesse-Biber, 2013). Feminist postmodernism represents an inclusive and non-judgmental approach to diversity and individuals' experiences (Snyder, 2008) and explores more possibilities to voice women's diversity.

A wide range of viewpoints can be identified in the literature regarding essentialist/constructionist approaches to feminism and materialism (Howie, 2010; Lykke, 2010; Van der Tuin, 2011; Zalewski, 2003). These contradictory epistemic positions play a key role in feminist theories. According to Lam (2015), feminism in the 1970s had an essentialist approach to gender but became more focused on identity in the 1980s. In subsequent decades, postmodernism and poststructuralism shifted feminist epistemology to focus more on the multiple realities, rather than binary approaches to gender issues (Lam, 2015).

Modernism believes in one truth and attempts to discover it through the use of positivist methods (i.e. quantitative methods such as survey, structured questionnaire and official statistics) (Zalewski, 2003). Given that feminist empiricism has roots in positivism, empiricist feminists contribute to knowledge through empirical research and believe that knowledge can be explored objectively (Hesse-Biber, 2007). Feminist empiricists apply feminist values in empirical investigation and explore the influence of a feminist approach to diminish gender prejudice in traditional positivist epistemology (Doucet & Mauthner, 2006).

While modernism has a central and linear approach to the world, postmodernism emphasises diversity, fragmentation, and subjectivity. Postmodernism reframes the way of looking

at biology by seeking a new perspective of social construction (Barad, 1998; Grosz, 2005; Hird, 2009).

Feminist postmodernism challenges the binary notions of the modernist era, including man and woman, subject and object (Hesse-Biber, 2011; Leavy, 2007). Feminist postmodernism challenges the gender norms construction (Cosgrove, 2003) and the essentialist perspectives of empiricism (Leavy, 2007). According to Leavy (2007), from a feminist postmodernist lens, cultural and historical gender differences are viewed as socially constructed. Consequently, the intersection of feminism and postmodernism results in the respect of women's variation (Hartsock, 1998).

Feminist postmodernism attempts to expand feminism to include women with a wide range of identities and also recognises that women are different in colour, ethnicity, sexual orientation, religion and cultural backgrounds, instead of considering all women in one category (Snyder, 2008). It considers gender as a system of meaning that is socially constructed (Butler, 1990). Therefore, feminist postmodernist scholars put aside the modernist viewpoint for objective truth and apply new possibilities to explore women's experiences. In doing so, the postmodernist approach, as opposed to the positivist way of knowledge production (Nicholson, 2013), recognises that there are multiple realities; thus, attempts to understand how realities are historically, culturally and socially constructed, and shape cultural and societal aspects of subjective experiences.

Feminist postmodernism not only refutes a binary approach to gender, but it also explores the way women's diversity shapes their lives (Hesse-Biber, 2013; Leavy, 2007). Consequently, I applied a feminist postmodernist epistemic position to explore new possibilities for women's experiences by seeking to discover how their meaningful mothering experiences are constructed. Viewing the world through a feminist postmodern lens allowed me to explore the mothering experiences of women with SCI as a minority group who may not only

experience discrimination from men, but also may be seen as invisible or experience discrimination from other women.

3.3 Research theoretical framework

This section starts with an overview of two main disability theories: the medical model and the social model of disability. Following this, I position the use of the social model of disability in this research, and describe how it is used to underpin feminist disability theory as the theoretical framework.

3.3.1 Disability theories

The medical and social models of disability are the two main disability theories (LoBianco & Sheppard-Jones, 2007). There are numerous theories which stem from these two main models of disability.

The medical model identifies disability as a physical, sensory, cognitive, and mental impairment that affects an individual's ability; thus, it considers disability as an individual deficiency (Albrecht et al., 2001) and a functional impairment (Marks, 2000; Palmer & Harley, 2012). Given the medical model of disability defines disability as an illness or injury which needs to be cured (Areheart, 2008; Dokumacı, 2019; Forhan, 2009; LoBianco & Sheppard-Jones, 2007; Marks, 2000; Mitra, 2006; Rutherford et al., 2001; Thomas, 2010), this approach seeks medical interventions focusing on the person with the disability, rather than social changes with respect to disability.

According to Terzi (2004), the medical model identifies individual impairment as an abnormality limiting a person's ability. From the medical-model perspective, an impairment influences the individual's autonomy; thus, the lack of individual autonomy results in restricting a person's participation in society (Bunbury, 2019). This approach can lead to identifying disabled individuals as inferior and dependent people (Finkelstein, 1998).

In contrast to the medical model of disability, the social model identifies disability as an interaction between an individual and their environment. The social model of disability considers society as playing a key role in the notion of disability (Bingham et al., 2013; Brandon & Pritchard, 2011; Coles, 2001).

From the social-model perspective, there is a distinct difference between the notion of disability and impairment (Haegele & Hodge, 2016). According to the social model, disability is not an individual's body malfunction (Barney, 2012; Roush & Sharby, 2011) but is a social construction which results in people's exclusion from participation in the community (Bingham et al., 2013; Goodley, 2001). While the medical model of disability focuses on disability as an individual deficiency, the social model of disability makes a concentrated effort to describe disability as a social construction instead of a medical issue (Titchkosky, 2000).

Given the social model of disability describes disability as a social construction, rather than an inherent deficiency, the social model challenges the social exclusion of disabled people and investigates what types of barriers exist and how these shape social activities and restrict disabled people's engagement in society (Mackelprang & Salsgiver, 2016). As it was echoed by many social disability activists –'Nothing about us without us', the participation of disabled people and giving voice to their experiences play a significant role to diminish the oppression disabled people experience (e.g., Charlton, 2000).

From the perspective of the social model of disability, disabling factors in societies, including societal attitudes and physical barriers, have a more restrictive effect on people's lives than just their bodies. Consequently, the social model seeks to find new possibilities for disabled bodies in the society, rather than focusing on the individual aspects of a body. Similar to the social model of disability, feminist

disability theory views disability as a social construction. However, feminist disability scholars have identified that both the medical and social models lack the recognition of gender in disability studies.

3.3.2 Feminist disability theory

This section draws on the contribution of Garland-Thomson's (2005) feminist disability theory, which considers that feminist interpretations provide a useful framework for analysing the gender-based dimensions of disability. Feminist disability theorists have critiqued not just the medical and social models of disability but also feminism for not recognising women with disabilities. Feminist disability theory applies a critical lens to challenge the social, cultural, political and gender constructions of disabled women.

In the early 1980s, the integration of feminism and disability was gradually noticed by feminists (O'Donnovan, 2010). Morris (1993) classified feminist development into two stages

in academic research. From Morris's (1993) perspective the first stage of the development was to add women as the subject of research to a male-dominant world.

The second and more significant feminist development was to challenge the current methodologies and paradigms as insufficient to explore women's realities. However, according to Morris (1993), feminist scholars overlooked the issues of disabled women. DePAUW (1996) considers the integration of feminism and disability is beneficial to enhance feminism in exploring women's issues such as their bodies and identities. According to O'Donnovan (2010), the appearance of feminist disability was confirmed by the National Association of Women journal and the feminist philosophy journal *Hypatia* in 2001.

Feminist disability studies argue that viewing the experience of disabled women solely through the lenses of feminism or the social model of disability can lead to ignoring the concerns of women with disabilities. As such, feminist disability studies

aim to diminish the binary approach to disabled and able-bodied people (Simplican, 2017). According to Thomas (1999), "Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psych emotional well-being" (p. 60). Thomas (1999) argues that the social model of disability has dismissed the cultural aspect of disability. She claims a feminist lens can enhance disability studies.

Similarly, Wendell (1989) claims a feminist approach can improve disability studies to better address disabled women's issues. According to Wendell (1989), the ethical, psychological and epistemological aspects of disabled women's lives should be considered in disability theories.

From Wendell's (1989) perspective, feminism, by challenging the dominant culture (i.e., male, able-bodied) and seeking social and cultural equality, can enhance the social model of disability. According to Wendell (1989), "disability is socially constructed from biological reality" (p. 107). Wendell (1989) considers disabled women encounter the dual oppression of being disabled and women in the able-bodied, male-dominated society. She highlights that feminist disability studies can help diminish the cultural oppression that disabled women experience.

Garland-Thomson (2002) argues,

> Disability, like femaleness, is not a natural state of corporeal inferiority, inadequacy, excess, or a stroke of misfortune. Rather, disability is a culturally fabricated narrative of the body, similar to what we understand as the fictions of race and gender (p. 5).

The significant impact of the integration of feminism and disability theory on analysing the experiences of disabled women is described in the literature (Garland-Thomson, 2002, 2005; Hall, 2002; Mays, 2006). According to Garland-Thomson (2002), the universal assumption of women's experience can lead to the oppression of minority groups of

women such as disabled, queer and black women. The feminist disability theory resists essentialism and sheds light on different women's identities, aiming to shed light on the way in which multiple identities (i.e., women, disabled, black, queer) intersect. According to Garland-Thomson (2005):

> Feminist disability studies scrutinize how people with a wide range of physical, mental, and emotional differences are collectively imagined as defective and excluded from an equal place in the social order. … This focus on how identity operates promoted an interest in the relation between bodies and identity. As a category of analysis, disability provides fresh ways of thinking about the complexity of embodied identity. Feminist disability studies defines disability as a vector of socially constructed identity and a form of embodiment that interacts with both the material and the social environments. (pp. 1558-1559)

Feminist disability theory establishes a theoretical outline to understand marginalised embodiments through historical and ideological perspectives (Hall, 2002) by avoiding a binary approach to people. According to Clímaco (2020), the binary approach, which stems from modernism's dividing people into black or white, ill or healthy, abled or disabled, and male or female, with one being superior and the other inferior leads to the marginalisation of people who are considered the 'other' such as women, elders or disabled people.

According to Clímaco (2020), the ultimate aim of many disability theorists of the social model, who were mainly western white men, was to diminish social and physical barriers to pave the way to independent living for disabled people. This is because, from their perspective dependency was perceived as an inferiority and a vulnerability (Clímaco, 2020). Davis (1984) argued that the interest in independent living has historical and social roots. According to Davis (1984):

> This reasoning is based on the dichotomy between masculine independence and

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feminine dependence as if only the polarized extremes were possible or desirable. The dichotomy is strongly reinforced by the cult of the body that at least implies that adequate adults will be strong and "fit," especially in physical, but also almost incidentally in emotional terms. The notion that the possessor of one trait cannot participate in its opposite leads to excesses at both extremes by people with disabilities and by their caregivers as well. (p. 1)

Garland-Thomson (2011) challenges the ideal of independence. She argues that since humans experience various degrees of difficulties and experiences throughout their lives, everyone experiences dependency. Ghai (2002) sheds light on the concept of independence from a cultural perspective. Ghai claims the concept of independent living from the Western perspective is insufficient to be applied to other cultures. For instance, due to the lack of infrastructure and equipment for disabled people in India, independence is not an attainable goal for Indian disabled women.

Although feminist disability studies have expanded the social model of disability beyond the social approach to disability in order to shed light on the intersection of disability and women's diversities such as gender, race or sexual orientation (Garland-Thomson, 2002), the area of feminist disability studies has also been associated with some tensions (O'Donnovan, 2010). For instance, Bunch (1988) considers, "feminists must stretch beyond, challenging the limits of our own personal experiences by learning from the diversity of women's lives" (p. 290). Moreover, Lindemann (2001) criticises the exclusion of cognitively disabled women from feminist disability studies. According to Carlson (2001), feminist disability studies have overlooked the experience of cognitively disabled women, which stems from the essentialist approach of feminist disability studies. Carlson (2001) considers, "there is less work on the dangers of perpetuating a form of essentialism that draws a sharp division between the cognitively able/disabled (p. 140)." She argues the essentialist approach leads to a division of women with disabilities to

those physically and cognitively disabled. Similarly, O'Donnovan (2010), highlights that feminist disability studies have neglected the experiences of women with invisible disabilities such as learning disabilities; thus, feminist disability studies have mainly focused on visible and physical disabilities.

Feminist disability studies identify that disability, like gender, is a system used to categorise some bodies as subordinate. According to Garland-Thomson (2005), feminist disability theory sheds light on how human variations relate to and are constructed by social meanings. Consequently, these meanings result in discriminatory practices, which can have an adverse impact on disabled women's lives. These social meanings are constructed through various sources, including material environments, which result in women's marginalisation, exclusion and discrimination. As I have shown in Chapter 2, a review of the literature has highlighted that there is a gap in providing for the needs of mothers with

disabilities in the material environment (Kaiser et al., 2012; Reid et al., 2003; Wint et al., 2016). According to Ahlvik-Harju (2016), normative standards in society lead to perceiving some bodies as normal and rejecting other bodies. Ahlvik-Harju (2016) claims feminist disability theory challenges the normative approach to people's diversity and sheds light on the way human's identities are shaped by their interaction with people and the material environment. Garland-Thomson (2011) argues the misfit interaction between bodies and the material environment can lead to disabling people who are not considered as normal.

Garland-Thomson's concept of misfit

In this research, I specifically aimed to explore the construction of meaningful mothering experiences through the interplay between mothers with SCI and child-caring products. In this section, I provide an overview of Garland-Thomson's concept of the 'misfit' (2011). I specifically chose the concept of misfit to underpin my research because it focuses on the

dynamic relationship between bodies and the material environment from the lens of feminist disability theory.

According to Garland-Thomson (2011), "the dynamism between body and world that produces fits or misfits comes at the spatial and temporal points of encounter between dynamic but relatively stable bodies and environments" (p. 594). The term 'misfit' emphasises the reciprocal interplay between things in the material environment and focuses on the disjuncture of the dynamic process of the interaction between a person and the material environment. Garland-Thomson (2011) highlights that our material environment is conceptualised and made for a dominant and uniform body. Consequently, the material environment does not fit bodies that are not included in the dominant criteria. This is because 'fitting' occurs between the body and the material environment when the material environment is designed and built for the body. Stairs are an example of misfitting to a person who uses a wheelchair, where the stairs are not

perceived as a connection way but a barrier. The misfit concept is useful to remind us that bodies are always dependent, based on the way the environment is designed to fit or misfit them (Garland-Thomson, 2011).

The concept of misfit stems from material feminism. Garland-Thomson (2011) explains her concept of 'misfit', "elaborate[s] a materialist feminist understanding of disability by extending a consideration of how the particularities of embodiment interact with their environment in its broadest sense, to include both its spatial and temporal aspects" (p. 592).

Binary notions of 'normal' and 'abnormal' stem from the normalising approach of scientific medicine to the body in the eighteenth century (Foucault & Sheridan, 1977). Davis (1997) considers the words 'normal', 'normality', 'average' and 'abnormal' appeared in the English language in the mid-nineteenth century.

Davis (1997), argued statistical knowledge in the modern era had a significant role in the conceptualisation of 'norm' as the majority of the population. Consequently, people with disabilities who statistically were not in the majority were considered as abnormal. According to Thompson (1997), the notion of normalcy resulted in devaluing certain disabled bodies: "in this economy of visual difference, those bodies deemed inferior become spectacles of otherness while the unmarked are sheltered in the neutral space of normalcy" (p.8). Solomos and Back (1996) consider that normalcy resulted in a hierarchical division to value people in society, whereby "people could be conveniently divided and classified not merely in terms of geographical origin or colour but equally by virtue of cranial capacity and shape" (p. 34). While the historical construction of normality was used to scale ideal or deviate people's bodies in society, this led to discrimination and oppression of people who were considered as abnormal or misfit.

Given that design based on a normative body results in the marginalisation of minority groups, the application of feminist disability theory and the concept of misfit in this research were useful to assist me in opposing the normative approach by exploring and voicing the experiences of mothers with SCI using child-caring products.

3.4 Overview of the methodological approach

A qualitative approach was chosen to explore the construction of meaningful experiences through the interplay between mothers with SCI and child-caring products. I applied a qualitative research approach for a number of reasons. First, a qualitative research approach suited the aims of this research project well since, according to Morse and Field (1996), qualitative research intends to help researchers to gain a deep understanding of opinions, experiences or values. Moreover, qualitative research focuses firmly on "the idea that meaning is socially constructed by individuals in interaction with their world" (Merriam, 2002, p. 3). As a qualitative researcher, I was

interested in how mothers with SCI construct their mothering experiences through products, and what meanings they attribute to these experiences. From my feminist disability position, I was interested in exploring how historical, cultural and social context shapes women's experiences of mothering with SCI.

A qualitative research approach supports the aims of the study through a feminist epistemological position, since feminist researchers epistemologically and methodologically focus on the issues of power, difference, voice, silence, and the complexities of the knowable world (Hesse-Biber, 2013).

Westmarland (2001) highlights qualitative research methods as being aligned with feminist epistemology; thus, they are appropriate methods for feminist research.

3.4.1 Participatory Action Research (PAR)

Participatory Action Research (PAR) aims to contribute to the knowledge through the interaction of theory and practice (Kemmis et al., 2013). A PAR approach aligns with feminist epistemology by respecting and giving voice to the participants, their perspectives and worldviews through their active participation in all stages of research (Grant & Giddings, 2002; Kindon, 2007; McCarthy & Wright, 2004).

According to Sherrod (2006),

> PAR scholars, drawing from feminist and critical race theorists, have worked to articulate a set of methods and ethics of PAR, the heart of which lies in understanding that people -especially those who have experienced historic oppression- hold deep knowledge about their lives and experiences and should help shape and questions, frame the interpretations, and style the research products that ultimately effect them most intimately. (pp. 457- 458)

As it was discussed earlier, feminist disability theory applies a critical lens to explore how social, historical and gender constructions shape the experiences of minority groups such as women with disabilities (Garland-Thomson, 2002). Similarly, PAR applies a critical approach to challenge the existing social, political and economic issues; thus, aims to improve the participants' problems through a socially interactive learning process with research participants (Kemmis & McTaggart, 2007).

According to Kemmis and McTaggart (2007), the socially interactive learning process refers to the process of exploring participants' actions, their interaction with people and the world, their values and interpretation and understanding of their world. In addition, a critical analysis of PAR cycles is useful to explore how hidden dominant social constructions shape participants' experiences (De Finney & Ball, 2016). Therefore, through a critical questioning of PAR process "people develop their power to perceive critically the way

they exist in the world with which and in which they find themselves; they come to see the world not as a static reality, but as a reality in process, in transformation" (Freire, 1997, p. 171).

Participatory action research encourages collaboration with participants through participatory cycles (Corbett et al., 2007) to explore their understandings, values and the way they interpret the world (Kemmis et al., 2013). In this thesis, I applied PAR as an overarching methodology with four distinct, but related, cycles of collaborative activities. In detail, the purpose of this research was as follows (Figure 3.2):

- To explore challenging mothering activities and meaningful mothering experiences for mothers living with SCI (Cycle I, problem identification)

- To better understand what constructs meaningful mothering experiences for mothers living with SCI (Cycle II, deeper understanding)

- To find new product opportunities for mothers living with SCI in relation to their meaningful mothering experiences (Cycle III, finding opportunities)

- To obtain participants' feedback on design prototypes and codesign process (Cycle IV, feedback)
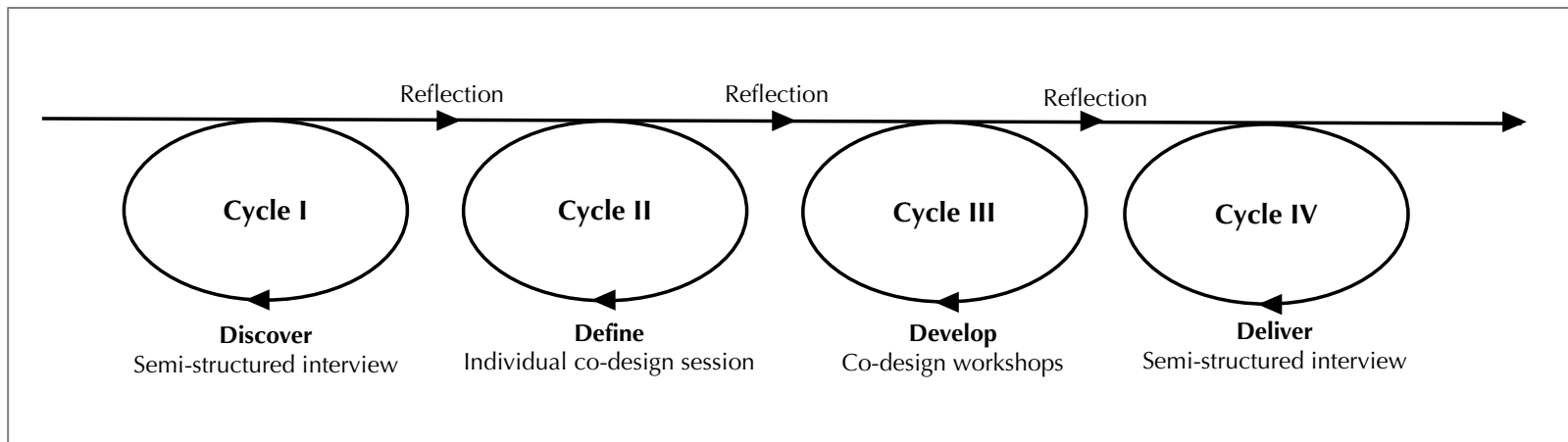
Figure 3.2. Overview of my research process showing the relationship between the four cycles.

Participation and action are the two key concepts of Participatory Action Research (Walker, 1993). The iterative cyclic model of PAR provided me with a better way of exploring the experiences of mothering with SCI and identifying new opportunities through a collaborative process (Walker, 1993).

PAR challenges the dominant knowledge and 'opens a window' into a new way of knowing by participation (Savin-Baden & Wimpenny, 2007). Consequently, the participants in the research were knowers of their mothering experiences and shared these through the PAR cycles. Hence this focus and approach align with critical feminist disability theory. In this research, the process of knowing was sharing "experiences through a dynamic process of action, reflection and collective investigation" (Gaventa & Cornwall, 2008, p. 74). Throughout the research cycles, the participants were considered as the knower of their experiences. Given that in PAR methodology, knowledge is a social construction (Savin-Baden & Wimpenny, 2007), participants were considered as coresearchers who shared their mothering experiences to inform the research questions.

3.5 Trustworthiness

This research applied Lincoln and Guba's (1985), four criteria to ensure the trustworthiness of the data. According to Lincoln and Guba (1985), the trustworthiness of a study can be obtained by demonstrating credibility, transferability, dependability and confirmability. Polit and Beck (2008) further define these aspects as follows: Credibility refers to the believability of research findings; Transferability is the applicability of the findings to other contexts and settings; Dependability refers to the state of consistency in the findings of a study, and confirmability is the extent to which a study's findings represent the participants' perspectives and experiences.

According to Creswell (2013), at least two of these four criteria are adequate to establish trustworthiness of a research.

In my research, trustworthiness was achieved during both the collection and the analysis of data. One way to ensure the credibility of research is to adopt well-established research methods, which have been successfully used in previous similar studies (Lincoln & Guba, 1985). This study adopted successful methods of data collection derived from similar previous co-design studies (Hussain, 2011; Hussain & Sanders, 2012; Sanders & Stappers, 2014; Sanders & Hirsch, 2014). While the focus of my research differed from these studies, both a participatory approach and the use of a co-design approach to data collection was shared.

According to Lincoln and Guba (1985), member checking is one means of ensuring the research's credibility. In this research, credibility through member checking was achieved by giving the participants a copy of the transcripts to read through in order to confirm they were an accurate record of their interviews and the co-design session during each of the four cycles. All participants agreed with the full content of their interviews and co-design sessions. At the beginning of each cycle, the findings from the previous cycle were shared with the participants and their agreement sort. As several participants were involved in all of the cycles, this confirmation process ensured the credibility of my findings. Also, excerpts of the discussions with the mothers have been referred to throughout this thesis to allow the mothers' voices and experiences to guide my argument.

Credibility was also gained through my prolonged interactions with the participants. My interactions with the participants were spread across the four cycles, which started in March 2018 and continued until February 2020. Eleven mothers took part in Cycle I, six out of eleven mothers participated in Cycle II, five mothers remained in Cycle III and four mothers remained in Cycle IV. This prolonged interaction helped me to build rapport with the participants, which proved to be

important as they were sharing their personal mothering experiences with me.

Given that my cultural background was different to that of the participants, the project had been discussed, before initiating the data collection, with Dr Huhana Hickey (disability activist and a Research Fellow in AUT's Taupua Waiora Centre for Māori Health Research), Dr Pani Farvid from AUTEC, and the Burwood Academy of Independent Living Research Review group based in Christchurch. These consultations helped ensure the sociocultural and physical aspects of participants were used to inform appropriate activities when collecting data. Specifically, Dr Huhana Hickey advised that I should include Māori mothers with SCI in my research, yet unfortunately, despite my efforts, the only Māori mother I came across through the course of my research did not express an interest in participation.

According to Lincoln and Guba (1985), transferability is established by keeping an audit trail, triangulation and reflexivity. The transferability of the research was achieved by providing rich, sufficient details of the participants through the four research cycles to create a detailed account of the research (i.e. thick description). In chapters 5, 6, 7 and 8, I have clearly described all the research stages from data collection, to research design, to reporting of the findings. In my research, field notes which had been made during the interviews and co-design sessions were also used, not only to document the events which took place, but also to describe the thoughts I had about the various issues of the research.

Audit trails are transparent descriptions of step-by-step stages of the research from data collection, to research design, to reporting of the findings (Lincoln & Guba, 1985). The material I used for the audit trail of my research included the interview/co-design session transcriptions, co-design activities, my visual mind mapping and analysis, and my field notes. I applied the audit trail to help me keep track of the changes that emerged through the four research cycles and to

reflect on the process of data collection in each research cycle and the findings.

Reflexivity refers to the effect of the researcher's position in relation to the research and the construction of knowledge in a step-wise process (Lincoln & Guba, 1985). Reflexivity was employed in the research process to enhance knowledge production and, consequently, to enrich the research outcome (Lincoln & Guba, 1985; Mauthner & Doucet, 2003). This was done by keeping a diary to record my interpretations, and reflections of various stages of the research.

In the research, I used my personal notes made during the interviews and co-design sessions to describe the thoughts I had throughout the various steps of the research. I made explicit mention at the beginning of the research my pre-understanding of feminism, including my beliefs and personal biases, which I have described in Chapter 1. In the process of reflexivity I was posing the following questions to myself: What do I understand by feminism? How can a feminist epistemic approach open a new window to find new opportunities for mothering with SCI? I kept a diary and made regular attempts to record my interpretations and reflections of the research. I was attentive to my role in the research process in relation to my feminist epistemic position, and the impact this had on my choice of research methods. I also acknowledged that my understanding of the implications of feminist positioning developed through the research (as described in Chapter 1).

3.6 General ethical concerns

This study was approved by the Auckland University of Technology Ethics Committee (AUTEC – Reference number 18/72 on 29/03/2018). In order to emphasise the importance of an equal balance of power between a researcher/designer and participants in the critical research, participants are considered as coresearchers; thus, participants are known as the subject of the research rather than being the research object (Guba & Lincoln, 1994; Scotland, 2012).

The participatory approach of my research helped me to avoid the hierarchical relations of power between myself and the participants. Additionally, my feminist epistemic position and the application of PAR methodology provided me with a democratic way of knowing by giving voice to the participants and avoiding objectification throughout the iterative research cycles. In this participatory research, participants were considered as the experts of their experiences (Sanders & Stappers, 2008).

Throughout my research, I adhered to the three ethical principles (Hudson & Russell, 2009) of partnership (i.e., ensuring benefit and respect for the participants), participation (i.e., clarifying the participants' roles and how the data provided by the participants benefited the research), and protection (i.e. protecting participants' identity and using pseudonyms). This included considering how my research considered each of the three principles of the Treaty of Waitangi[6] (Partnership, Participation and Protection) in the relationships between the researcher and other participants.

In Aotearoa New Zealand, ethics approval for all research conducted with people requires the three principles of the Treaty of Waitangi (i.e., Partnership, Participation and Protection). According to Hudson and Russell (2009),

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[6] According to Hudson & Russell (2009), the Treaty principles, Partnership, Participation and Protection, "have been widely adopted throughout government organisations as a mechanism to respond to inequalities in society that affect Māori. Government organisations have each, in their own way, interpreted the Treaty principles in relation to their spheres of activity. The Treaty of Waitangi is recognised as an integral part of New Zealand's ethical framework but its interpretation needs to reflect the ethical understandings of both parties, Māori and European, particularly in relation to the contribution that research can make towards addressing inequalities within our society" (p. 62).

In the context of research ethics, interpretations of the treaty principles should frame and provide space for both Western ethical concepts and Māori ethical concepts. It is important that the process of critical reflection in terms of a framework of research ethics in New Zealand keeps pace with the evolving practice of ethics and changing expectations that communities have of researchers (p. 63).

While none of the participants identified themselves as Māori, I had to consider the safety of the participants throughout the research process.

The principle of Partnership (Hudson & Russell, 2009) was enacted by protecting participants' data, privacy, values and norms throughout the research. By respecting the participants and being fair and true about my intentions in collecting the information, I endeavoured to ensure the participants would be agreeable and comfortable with the process and feel protected during and after the data collection (Rubin & Rubin, 2011). I attempted to establish a relaxed and trusting relationship for the participants to take part in the study by encouraging participants' active engagement as a subject of the research rather than being the object of the research. Interviews and co-design sessions with participants took place in a location of their choice (e.g., their home, office, etc.) as this was more convenient for them. Participants were invited to choose the activities in co-design sessions based on their interests and preferences. These co-design sessions, which I describe in detail in Chapter 4, consisted of different activities including sorting pictures and cards, post-it notes, coloured stickers, drawings and making objects (with materials such as cardboard, cloth or paper).

The principle of Participation (Hudson & Russell, 2009) was implemented by considering the prime role of the participants (as the experts of their experience) was to provide data through interviews and co-design sessions. Therefore, at each cycle of the study, through both the Participant Information Sheet (see Appendix B_1, B_2, B_3, B_4) and additional in-person explanation

where required, the participants were carefully informed of the aims of the study.

Furthermore, I answered participants' enquiries about my research during the recruitment and data collection phases. Participants were made aware they could withdraw from the study by informing me before starting the data analysis phase. Participants were informed that AUT Counselling Services was available free for those participants who might experience distress brought about by the research process. To my knowledge, none of the participants requested the use of this service. Following the Participant Information Sheet and Consent Form (Appendix C_1, C_2, C_3, C_4), I attempted to ensure respectful approaches in conducting the interviews and co-design sessions.

The principle of Protection (Hudson & Russell, 2009) was implemented through encouraging mutual respect and participant autonomy. The participants' Consent Form articulated that I would use the video recordings and photos of the session, either complete or in part, alone or in conjunction with any wording and/or drawings, solely and exclusively for the purposes of the research. However, participants' faces would be removed or blurred in any publications. The names of participants have been replaced with pseudonyms. Other identifying information such as participants' email, occupation and address would also be removed. The photos, videos and transcripts are stored on a password-protected computer and will be deleted six years after the study's completion. In addition, the transcriptionist, who transcribed all of the audio recordings to verbatim text has signed a Confidentiality Agreement (Appendix E). Once the interviews and co-design sessions had taken place, I shared the transcript of their interviews with the participants to allow them to revise any parts they felt were not representative of the session or they uncomfortable with and did not want to be included as part of my data.

3.7 Conclusion

This chapter describes the research paradigm and theoretical underpinnings. Throughout the research, Garland-Thomson's (2005), feminist disability theory was chosen to guide data collection and analysis. Participatory Action Research was applied as an overarching methodology within four distinct but related cycles to explore the interplay between mothers with SCI and child-caring products in the home environment. The study used a qualitative approach to data collection in order to uncover hidden aspects of participants' experiences. One-on-one semi-structured interviews were applied in Cycle I and Cycle IV. A co-design method was used in Cycle II and Cycle III. In the next chapter, I outline my research design including a detail description of research participants, data collection and analysis methods. The chapter finished with the research's ethical considerations and the steps taken to ensure the participants' privacy.

Chapter 04. Methods

Introduction

In this chapter, I discuss the process of how I undertook this research. This chapter begins with a description of the research participants and the inclusion criteria in section 4.1. Then, section 4.2 describes the research methods including semi-structured interviews, co-design and the procedures that were followed to carry out this study. Subsequently, the method used for data analysis is discussed in section 4.3.

As I described in Chapter 3, Participatory Action Research was applied as an overarching methodology with four distinct cycles by related activities. Figure 4.1 shows the aims and relation between the research cycles.
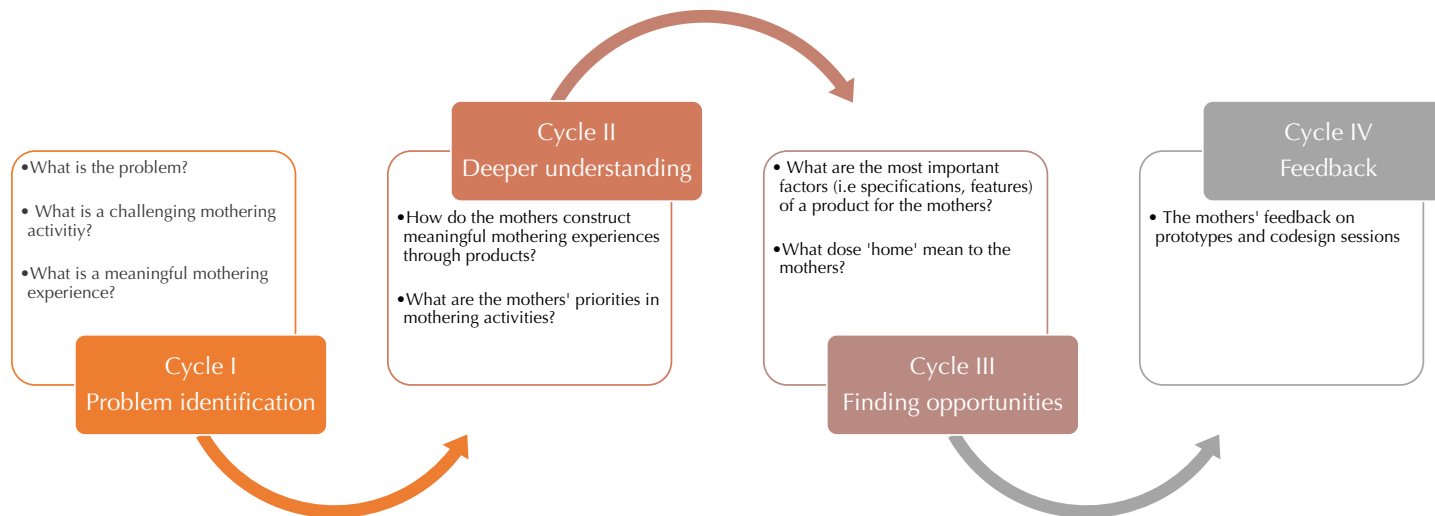
Figure 4.1. The aims and relation between the research cycles

The first cycle of research set out to explore what participants considered meaningful mothering experiences as well as those activities they considered challenging. In this research, a challenging activity refers to a mothering activity that was described by participants as being difficult or needing great physical effort. A meaningful experience refers to an experience that was described by participants as an intimate and continuous relationship between a mother and her child.

Earlier studies highlight the challenges that disabled mothers experience in performing mothering activities (e.g., Alexander et al. , 2001; Kaiser et al., 2012; Powell et al., 2019; Reid et al., 2003; Wint et al., 2016). The findings of previous studies regarding the mothers' challenges led me to assume that these challenging experiences would impact on the construction of meaningful mothering experiences However, I tried to avoid my assumptions about the experience of mothering with SCI and initiated the research by aiming to give voice to the mothers as the knower of their experiences- in other words, for

them to identify those activities that were most relevant to them.

In Cycle II, I aimed to gain a deeper understanding of how the mothers constructed meaningful mothering experiences. I applied Sanders & Stappers's (2008) co-design concepts perspective. I applied co-design as a method to explore the mothers' experiences through a participatory way of gaining knowledge. In Cycle I, I had identified that the mothers alluded to a difference between what consisted of a challenging mothering activity and a meaningful mothering experience. Consequently, the main aims of the second cycle were to further explore the mothers' priorities associated with their mothering tasks, and thus to focus more on exploring what made experiences meaningful to the mothers.

In the third cycle, I built on the findings of cycle II, which provided me with a better understanding of the mothers' experiences, needs, and priorities. One of the significant findings in the second cycle was the mothers' interest in using

a product instead of relying on a third party to care for their child. Hence, the second cycle led to a change in my focus from only concentrating on child-caring products to explore products more broadly. This included expanding the notion of product to be any 'fit' product/ furniture in the home environment. As it was described in Chapter 1, in this research, a 'fit' product draws on Garland Thomson's (2011) notion of fit and refers to products that were considered usable by the mothers and met their physical needs.

Co-design is described as a democratic way of knowing, and used to encourage non-designers to participate in design processes, from problem definition to ideation, conceptualization, detail design, and final feedback (Fuad-Luke, 2009). In doing so, in Cycle IV, I shared the developed ideas of the 'fit' products with the mothers. The aim of Cycle IV was to hear their feedback on how I gave form to what they had expressed through the research as an integral part of data analysis and validation of my study to complete the research cycles.

The iterative process of PAR within four research cycles provided me with better insights into the mothers' world of mothering. Giving voice to the mothers helped me to avoid objectification of the mothers in the research process through their active participation in all the research cycles. The participatory approach of my research assisted me to better explore participants' dreams, values and better gain insight into the way they perceived their mothering. This was because, throughout my research, the mothers were not considered merely as a source of information input into the co-design process, but rather as experts of their experiences who were invited to participate actively with me to shape the direction of the research. Consequently, the mothers shared their mothering experiences and perspectives, contributed to the idea generation, idea development, and decision making.

4.1 Research participants

In the following section, the research participants are introduced with an initial explanation of how the participants were recruited.

The data collection in the first cycle consisted of individual semi-structured interviews with participants. Participant recruitment was initiated by contacting both local and national disability organisations. I sent over 50 emails to a wide variety of national and local disability organisations, centres, networks and activists asking them to help with the recruitment process and to distribute an advertisement inviting participation to their members. I received responses from only a small number of these organisations, including YES Disability Centre, CCS Disability Action, AUT Disability Support, Burwood Academy of Independent Living (located in Christchurch) and New Zealand Spinal Trust. These organisations placed the advertisement of the research on their social networks. In addition, my supervisors and I used personal networks to invite participants to take part in the research.

Inclusion criteria are defined characteristics that determine who will be included in research (Salkind, 2010). Given that the aim of Cycle I was to explore mothering experiences with SCI, the following criteria were initially used to recruit the participants in Cycle I:

- Be either tetraplegic[7] or paraplegic[8];

- Aged between 20 to 50 years;

- Have experienced mothering with SCI;

- Have children aged between 0 to 5 years old.

- Reside in Aotearoa New Zealand

Given that there were so few potential volunteer participants who met the initial inclusion criteria, three further criteria were added; (I) that not only mothers with SCI in Aotearoa New Zealand, but also mothers with SCI who met the inclusion criteria from overseas; and (II) having children aged between 0 to 5 years old was extended to having children aged between

0 to 16 years in age; (III) participants' age was extended from 20-50 years to 20- 52 years old.

As well as placing advertisements to identify potential participants, I also searched extensively through the Internet to find mothers with SCI around the world. I used different terms to search through the internet such as mothering with SCI, mothers in wheelchair, mothering and wheelchair, physical disability and mothering. I found some short video files and pictures of mothers with SCI in relation to their mothering experiences. Hence, I identified potential participants mainly

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[7] Tetraplegia "refers to impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord due to damage of neural elements within the spinal canal. Tetraplegia results in impairment of function in the arms as well as typically in the trunk, legs and pelvic organs (Kirshblum et al., 2011, p. 536).

[8] Paraplegia refers to "impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to damage of neural elements within the spinal canal. With paraplegia, arm functioning is spared, but, depending on the level of injury, the trunk, legs and pelvic organs may be involved." (Kirshblum et al., 2011, p. 536).

through their publicly available weblogs, Facebook, YouTube (after watching their videos about mothering with SCI). I sent over 80 emails to mothers with SCI who had shared their mothering experiences publicly on the Internet.

Potential participants who expressed an interest in participating were invited to take part in the study. These participants were invited through a formally digital or printed invitation with details of recruitment including the Participant Information Sheet (See Appendix A₁).

Incidentally, the process of searching for participants made me more familiar with online resources for mothering with SCI. I found the online resources were very limited. This was because in many cases mothers individually shared their experiences by uploading their videos or pictures on the internet, consequently this suggested that the online resources were not organised to provide a comprehensive resource/ network for mothering with SCI.

Given that the aim of qualitative research is to gain deep insight and understanding rather than making statistical generalisations, small sample sizes are often used (Creswell, 2007). In total, eleven mothers with SCI who had volunteered to participate in Cycle I were selected. Three of the mothers were from USA and eight of the mothers were from four main cities in Aotearoa New Zealand.

The mothers were aged between 32 and 52 years. Five mothers had one child each, three mothers had two children and one mother had three children. The ages of the children ranged from 2 to 16 years at the time of the interview. Five of the mothers were tetraplegic and six were paraplegic. All mothers were wheelchair dependent and five of the mothers reported having difficulty with dexterity. Eight mothers had manual wheelchair and three mothers used electric wheelchair. Three of the mothers were in full-time employment, four were in part-time employment and four were full-time mothers.

In Cycle II, potential participants were those recruited in the first cycle of this research and who had stated their interest in participating in the second cycle Two of the mothers were tetraplegic and four were paraplegic. Potential participants were sent the Participant Information Sheet (Appendix A$_2$) by email inviting them to participate in the second cycle of the study. A convenience sample of six women each participated in an individual co-design session. As described earlier, I applied co-design not only as a method but also as a participatory way of knowing. The collaborative nature of co-design process emphasises on equality and balanced power relation (Donetto et al., 2015; Walsh, 2018). This approach can empower marginal groups including mothers with SCI by giving voice to their experiences.

The main reason for conducting the co-design sessions individually was to provide equal opportunity and time for all the potential participants who may not have been able to participate in the research because of living in different cities, physical disability, privacy considerations or other reasons that might prevent them from attending at a specific time and location for a co-design session. Therefore, I had more time with each participant and activity in the individual co-design sessions. Due to the need to physically interact with the participants, all the participants in the second cycle lived in Aotearoa, New Zealand. Four mothers lived in Auckland and two mothers lived out of Auckland. I travelled to their cities (i.e. the location of their choice) for these individual co-design sessions.

In Cycle III, potential participants were those recruited from the second cycle who had stated their interest in participating in the third cycle. One of the mothers were tetraplegic and four were paraplegic. Potential participants were sent the Participants Information Sheet (Appendix A$_3$) by email. Given that the third cycle was co-design workshops and due to the need to interact with other participants, all the participants in the third cycle lived in Auckland, Aotearoa New Zealand.

Consequently, those mothers who were not able to travel to Auckland, did not participate in the third cycle. Ultimately, five mothers participated in a co-design workshop.

I intended to conduct one workshop with all five mothers for the third cycle. Given that some mothers were available in the morning and some were available in the evening, for the convenience of the mothers, I split the co-design workshop into two sessions. Since only one mother out of five was tetraplegic, I had no choice to split the co-design workshops based on the mothers' levels of spinal cord injury.

Two mothers attended the morning session, and three mothers attended the evening session. The morning session was held at Yes Disability Centre as this location was convenient and accessible for the mothers. One of the mothers was tetraplegic and one was paraplegic. The evening session was held at one of the mothers' homes. The mother voluntarily offered her home, and it was accessible and convenient for the other two

mothers. All the mothers in the evening session were paraplegic.

In Cycle IV, potential participants were those who participated in the third cycle of this research and who had stated their interest in participating in the fourth cycle. Potential participants were sent the Participant Information Sheet (Appendix A$_4$) by email. Four mothers participated in one-on-one interviews. One of the mothers was tetraplegic and three were paraplegic. All the participants lived in Auckland.

4.2 Data collection

According to Guba (1990), the democratic research approach and participants' experiential knowledge leads to both new discovery and known knowledge. Considering my feminist epistemological position and participatory action methodology in the research, the way of knowing and the role of knower were two key concepts held throughout my multi

method qualitative research. In this research, I applied semi-structured interviews in Cycle I and IV.

I used a co-design method in Cycle II and III. Overall, the four cycles of data collection were spread over two years. Data collection started in April 2018 and ended in February 2020. Table 4.1 summarises the data collection procedure of the study.

Table 4.1. Data collection methods

Research cycles	Data collection method	Number of participants	Length of session	Timeline	Location
Cycle I	Semi-structured interviews	11 participants	1-1:30 hour	April- May 2018	3 participants from overseas and 8 participants from Aotearoa, New Zealand
Cycle II	Individual codesign sessions	6 participants	1:30 hour	November-December 2018	Aotearoa, New Zealand
Cycle III	Codesign workshops	5 participants	2 hours	May 2019	Aotearoa, New Zealand
Cycle IV	Semi-structured interviews	4 participants	1 hour	February 2020	Aotearoa, New Zealand

4.2.1. Interviews

In Cycle I and IV, I chose one-on-one interviews as the main data collection method to explore participants mothering experiences, needs and dreams. Examples of the topic guides of interviews are included in the appendix (Appendices D_1 and D_4).

Structured interviews are often used in quantitative research and semi-structured are applied in qualitative research (Crabtree & Miller, 1999; Fontana & Frey, 2005) to better understand the participants' world (DiCicco-Bloom & Crabtree, 2006). A semi-structured interview allowed me to explore challenging mothering activities and meaningful mothering experiences with SCI from the mothers' perspective.

In Cycle I, the mothers who lived in Auckland were interviewed in a location of their choice (e.g. their home, office, etc.) for their convenience. Mothers who did not live in Auckland were interviewed via Skype or by phone (based on the participants' choice). The semi-structured interviews were all conducted by me and lasted from 1 hour to 1 hour 30 minutes. Before each interview, I checked if a participant needed any further information about the study, and obtained their written consent. Each interview was audio recorded then transcribed with the mothers permission. Field notes were also made during the interviews The interviews were conducted in a natural conversation style and thus I believe that my enthusiasm and respect for what participants were saying appeared to encourage the mothers to share their experiences generously.

The one-on-one interviews started by asking each participant for their general demographic details including age, the level of their SCI, occupation, number of children they had and the age of their children. These questions were aimed to collect background demographic information about each participant. Then, I initiated each one-on-one interview with a broad and

open-ended question. I asked open-ended questions to avoid imposing my personal perspectives on the participants' experience. I encouraged participants to describe their mothering experiences in depth (Giacomin, 2014). During the interviews, I asked non-directive and unplanned follow-up questions to learn more about participants' mothering experiences as the conversation developed (Warren & Karner, 2005).

In Cycle I, I explored participants' opinions on the notion of being a mother, their challenging mothering activities, what made the most meaningful experiences and finally, what age and behaviour of child they found most challenging. I also asked participants' their perspectives on mothering and their use of child-caring products as a mother with a SCI. I was particularly interested in exploring 'How products would construct meaningful mothering experiences'.

During interviews, I responded to participants by paraphrasing their words to hear more explanation (Warren & Karner,

2005). For instance, a participant considered her experience of having to rely on a third party as a 'heart-breaking' experience. I was particularly interested in a deeper understanding of what she meant by 'heart-breaking'. This response helped to encourage participants to explain more about a moment I was interested in. I gave participants time to verbalise their response and I did not interrupt them, even if a participant talked off topic. The more a mother talked, the more I became familiar with her world.

The process of interviewing in cycle IV was similar to that undertaken in Cycle I. In Cycle IV, I aimed to hear the mothers' feedback on prototypes and our co-design sessions. I conducted four one-on-one semi-structured interviews with the mothers. All the interviews were conducted by me and lasted one hour.

4.2.2 Overview of co-design

In the critical paradigm, participants are considered as coresearchers and their collaboration plays a decisive role throughout the research to avoid participants' objectification (Luck, 2007). PAR methodology applies a dialectical approach to collaborate with participants; thus to prevent participants' marginalisation through the research process. In this research, I applied co-design as a research method to explore the interplay between mothers with SCI and child-caring products in home environment in Cycle II and III. The iterative process of co-design stemmed from Participatory Action Research (PAR) to include participants' experiences beyond the basic design process (Sanders & Stappers, 2014).

Participatory approach to design process has been used in several disability studies. These studies acknowledged that users' participation through design process enhances the role of a user from a design solution recipient to a participant through the design process (Luck, 2007). This epistemic shift to design is a participatory way of knowing (Luck, 2007); thus, a participant is considered as a knower of their experiences through the design process (Sanders & Stappers, 2008). For instance, (McDonagh & Thomas, 2010), considered the important role of users' participation as an insightful source to gain a deeper empathy with participants through a design process.

Co-design had been used by several researchers working with participants who live with different types of disability. For example, Hendriks et al. (2015) applied a co-design process with participants with cognitive or sensory disability. Hendriks et al. (2015) claimed that their participatory approach toward design process lead to voice marginalised groups more effectively. Morales et al. (2018) applied co-design to design adaptive sex toys for people with motor disabilities. According to Morales et al. (2018), the co-design process was useful to better understand participants' own experiences. Consequently, new design solutions were generated based on

participants' concepts and needs. Gaudion et al. (2015) found their co-design process was an inclusive approach to explore autistic adult participants' needs. Mäkelä et al. (2019), applied co-design to evaluate the feasibility of a new intervention for people with traumatic brain injury. Similar to Hendriks et al. (2015), Mäkelä et al. (2019), claimed that co-design provided a space to include marginalised groups to hear their voice. Wilson et al. (2015) considered co-design as a tangible language approach to communicate with participants with aphasia and find creative ideas and solutions.

Norman (2005) highlights that people were historically expected to adapt themselves to the products they used. Nowadays, new approaches to the design of products looked for ways to ensure that products meet users' needs and experiences more effectively. In doing so, the design discipline has shifted from not only focusing on products and their manufacture, but also the design process (Suri, 2003).

According to Banham (1972), the Design Research Society (DRS) was the first design society to use the term 'design participation,' in 1971. Design participation was used to introduce users as participants in the design process. Simonsen and Robertson (2012) define participatory design:

> "a process of investigating, understanding, reflecting upon, establishing, developing, and supporting mutual learning between multiple participants in collective 'reflection-inaction'. The participants typically undertake the two principal roles of users and designers where the designers strive to learn the realities of the users' situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them." (p. 2)

Participatory design is rooted in Scandinavia (Kensing & Blomberg, 1998; Spinuzzi, 2005). According to Hussain et al. (2012), there were various attempts has been done in Scandinavia to increase the effectiveness of computer systems in workspaces through the collaboration between labour

unions and designers of computer systems. These attempts aimed "to allow workers to determine the shape and scope of new technologies introduced into the workplace." (Spinuzzi, 2005, p. 163). In the beginning, participatory design was an attempt to introduce a democratic trend at workplaces that supported skilled workers to work more effectively with computers (B∅ dker & Sundblad, 2008; Sanders & Stappers, 2008).

Rothschild (1999) highlights that the initial stem from participatory design was in feminist activity against regarding social injustice and male domination in the 1970s. Robertson and Simonsen (2012) consider feminism as one of the foundations of participatory action, which subsequently led to the development of participatory design. Feminism and participatory design both aim to bring a democratic perspective and voice to marginalised groups (Bardzell, 2018); thus, both feminism and participatory design aim for social justice by respecting people's diversities. According to

Robertson and Simonsen (2012) feminist participatory actions, such as giving voice to women's experiences and invisible views, have an underpinning role that leads to users' participation in the design process.

There is a large body of literature on finding creative solutions through participatory design methods (e.g., Bannon, & Ehn, 2012; DiSalvo et al., 2012; Manzini, & Rizzo, 2011). Nowadays, participatory design is an approach to design that is more often directed towards the design of useful and innovative products, systems and services for all domains of people's lives (Hussain & Sanders, 2012). This approach respects people as experts and involves them in the design process; thus does not consider people solely as consumers (Sanders & Stappers, 2014).

According to Sanders and Stappers (2014), there was a rapid adoption of design methods that considered the role of users in design processes. Consequently, a participatory approach to design represents an ideological shift in the role of users in

the design process; from being a design recipient to being involved in the process of design and decision making (Luck, 2007). This collaboration of non-designers throughout the design process provides an opportunity for designers to discover hidden aspect of users' experiences through the use creative design processes such as making prototypes and objects (Sanders & Stappers, 2014).

Consequently, prototyping has become an activity that both designers and co-designers can engage in during all phases of the process (Sanders & Stappers, 2014). Considering the key role of users in a co-design process, Sanders and Stappers (2008) describe co-design as a "collective creativity as it is applied across the whole span of a design process" (p.6) (Figure 4.2).

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Figure 4.2. Co-design process. Source: (Sanders & Stappers, 2008, p.6).

I applied a co-design method that focused on including non-designers throughout the design process to gain a deeper understanding of their experiences and needs, as well as to involve them in finding creative design solutions (Sanders, 2013). Given that participants in the co-design process are experts of their experiences (Sanders & Stappers, 2008), in this research mothers with SCI took on the role of experts, playing a key role in creative design solutions in this research.

In this research, the application of feminist epistemology provided the lens and informed the methods that were most appropriate to explore women's experiences. In other words, this was an approach to designing for women, with women and by women. As I have proposed in Chapter 3, the participatory approach of a co-design process aligns well with feminist disability theory, in giving voice to marginalised groups and social justice by respecting individuals' diversities. Similar to the co-design process, feminist scholars not only generally challenge the hierarchical research approach of researcher and researched but also they seek for more equal and fair research processes (Gatenby & Humphries, 1996; Hammersley, 1992; Lennie, Hatcher, & Morgan, 2003). Feminist studies consider that the voices of participants should be heard without preconception (Doucet & Mauthner, 2006). Similarly, the co-design process aims to avoid previous assumptions on the nature of the design problem and seeks to explore design solutions with participants throughout the design process (Sanders, 2006).

Generative Tools

As a method, co-design provides a wide range of tools to gain deep insights of participants. While the traditional design process applied tools such as interview and observation to explore users' needs and thoughts, the focus of co-design processes are on 'what people make' and provides a tool in order to gain a better insight into users' experiences (Sanders, 2000). Making prototypes is one of the complementary tools used in co-design processes which has been growing recently.

Making objects and generative tools can be applied by non-designers to clarify the future experiences through design process (Sanders & Stappers, 2014). Generative tools can be applied as a visual language and a new way of communicating with people (Sanders, 2006). This approach not only enables designers to capture those hidden aspects that people fail to express in words, but also helps designers to use a new language to explore participants' thoughts, feelings, and experiences (Sanders, 2002).

According to Visser et al.'s (2005) findings, co-design tools can uncover the hidden needs of the users. The researchers identify that generative tools discover the deeper levels of users' world. This provides useful insights for a designer to access the experiences that are otherwise not easy to be expressed in word s or by observation (Figure 4.3).

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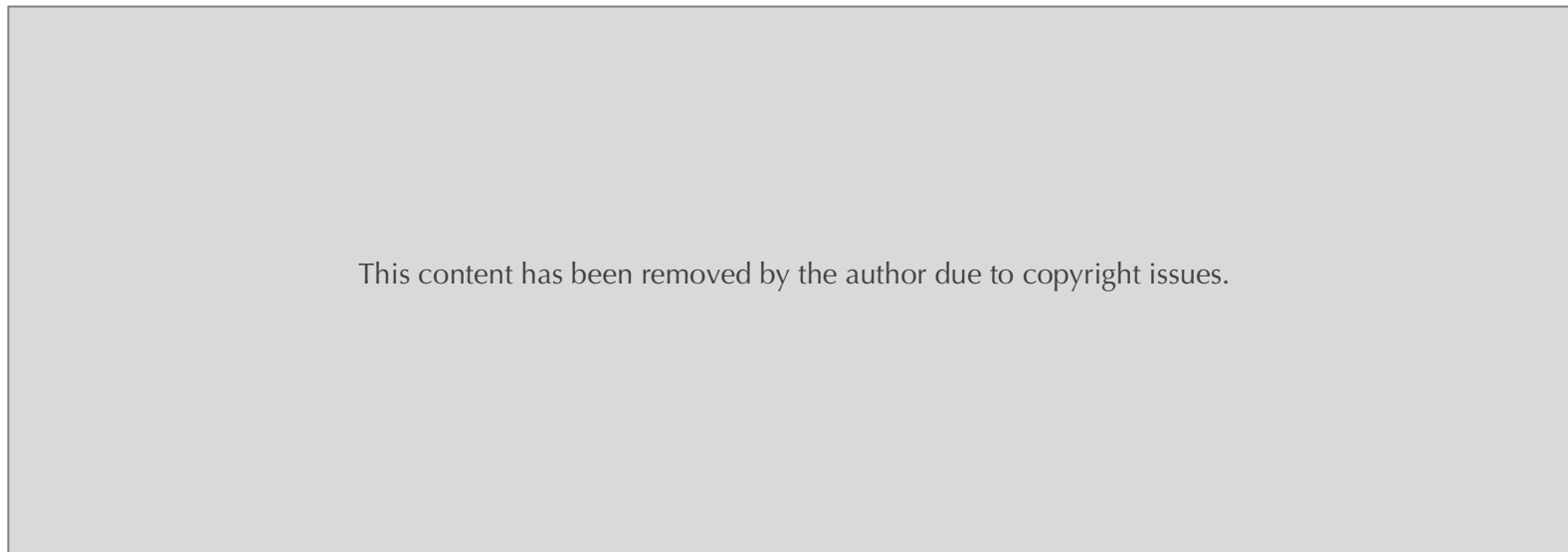
Figure 4.3. The level of knowledge acquired about users' experiences by different techniques (Visser et al., 2005, p.123).

In Cycles II and III, I used generative tools as a part of the codesign process, which included sorting pictures and cards, post-it notes, drawings and making objects with materials such as cardboard, cloth or paper to explore the mothers' unspoken feelings and experiences. Figure 4.4 shows a summary of the activities that have been done in Cycles II and III.

Thematic analysis was applied to analyse the data (Section 4.3).
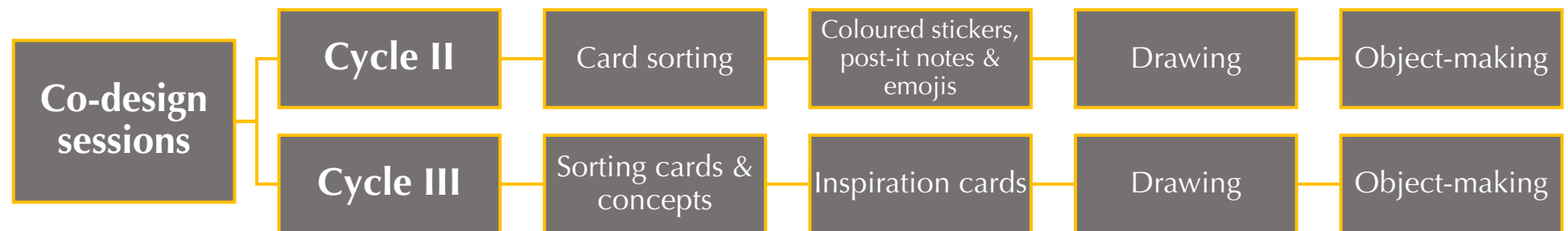
Figure 4.4. A summary of the co-design activities in Cycle II and III.

The generative tools in co-design method helped me to communicate with the mothers more effectively. According to Sanders's (2002) findings, 'making tools' such as maps, 3D objects, diagram, flowcharts, and cognitive models have a significant role in uncovering latent layers of users' experiences. I used generative tools not only to learn and build knowledge without asking direct questions, but also these generative tools provided me with creative ways to help the mothers form their thoughts and feeling and generate new ideas. The codesign activities were undertaken based on the mothers' choices, interests and physical ability.

With the mothers' permission, I photographed, audio recorded and video-recorded the activities in each co-design workshop. The video recordings and photos of the workshops were used in the subsequent data analysis.

4.2.3 Co-design procedure in Cycle II

The following sections introduce each generative tool used in Cycle II and explain why each tool was chosen. According to Labattaglia (2019) seven principles may be used to frame accessible co-design. These include "using appropriate language, make participation accessible, allow more time, person first-disability second, take a thoughtful approach and reflect continuously" (p. 131).

In the co-design sessions, in order to ensure that the sessions were most accessible, I provided a range of activities and materials including cards, coloured stickers, play dough, cloth, paper and cardboard for the mothers to form their ideas based on their interest. During co-designing with the mothers, I reflected with the mothers by asking why, what and how to explore their ideas and experiences in relation to mothering in greater detail (Giacomini et al.,2000). The required time for

each activity in a co-design session was the choice of the mothers. I asked each mother if she needed further assistance when using each generative tool.

The main limitation identified in my study was co-design's assumption of able bodied participants. Several of the generative tasks required the use of fine motor skills. However, I found that individual co-design sessions were useful as it was easier to adapt co-design activities according to the participants' physical abilities and personal needs. This was because some co-design activities, such as making objects and drawing, were not as accessible for the two tetraplegic mothers. As the aim of co-design activities was to use the most appropriate tools to enable participants to express themselves (Sanders & Stappers, 2008); I used generative tools based on the physical abilities of the participants. In this case, the two tetraplegic mothers shared their ideas verbally and I made the objects based on their ideas in our co-design sessions. This strategy assisted me to both make the codesign accessible and

to better explore the mothers' needs and experiences through the co-design process. Findings of the limitations of the co-design process are further discussed in Chapter 9 (see section 9.3.5).

Card sorting

Participatory design studies acknowledged the useful role of card sorting to prioritise and classify participants' opinions, values and experiences (Grenville, 2014; Katterfeld et al., 2012; Mulvale et al., 2016). I used card sorting as a way to help the mothers sort, cluster and categorise different mothering activities. The aim of card sorting was to explore the relationship between a mothering activity and a body

posture[9]. These findings were used to in the next cycle (i.e. Cycle III) to explore new design solutions and opportunities for the mothers.

Card sorting started with a presentation of cards arranged into two groups, cards of body postures and cards of mothering activities. Cards of mothering activities included sixteen cards showing a variety of mothering activities that the mothers had identified in Cycle I (e.g., bathing, breastfeeding, changing nappies, playing with a child, sitting on the ground and spending time with a child, clothing, feeding, sleeping, drawing, doing creative artworks, calming a child, physical proximity, kissing and cuddling) (Figure 4.5). Each card was 10cmx10cm in size.

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[9] In the field of Ergonomics, posture refers to the position of the body such as sitting or bending (Pheasant, 1991).

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.   Figure 4.5. Card sorting, Individual cards showing different mothering activities that were identified in Cycle I.

Then, the mothers were invited to sort mothering activity and categorise the cards under the relevant body posture card/s (Figures 4.6 and 4.7). Cards of body postures included bending, wheeling and carrying a child, transferring from a wheelchair to a chair/ ground and dexterity. The body postures were orientated around the four dominant mothering activities identified in Cycle I.

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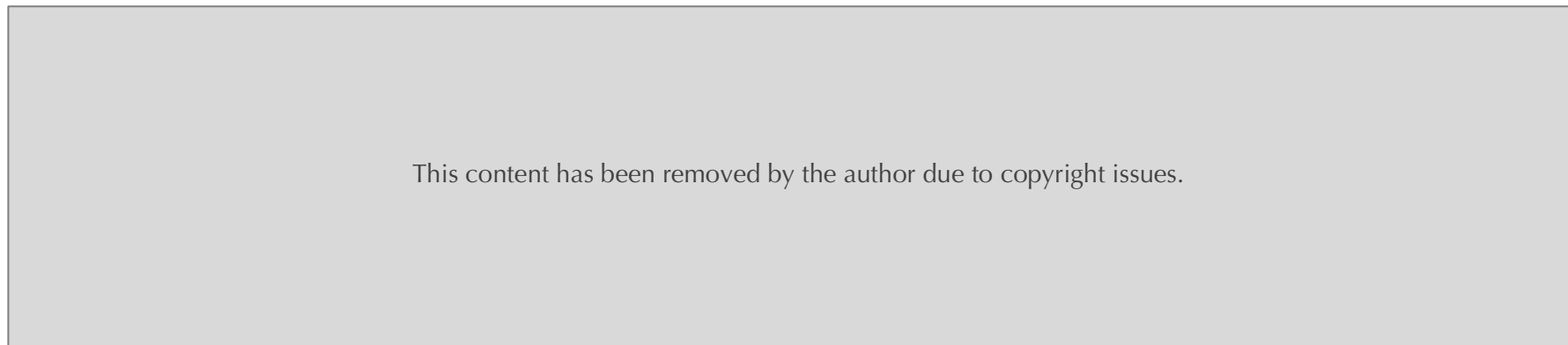
Figure 4.6. Card sorting, Individual cards showing four body postures that were related to dominant mothering activities identified in Cycle I.

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Figure 4.7. Card sorting, Through cards sorting, the mothers categorised mothering activity cards under the related body posture cards.

The mothers were asked to explain the relationship between mothering activities and body postures while card sorting. For instance, all the mothers considered the activities that were related to going down to the ground (such as playing with a child on the floor) as very challenging. Maintaining balance was considered to be the main challenge when transferring from a wheelchair to the ground (and then getting back to the wheelchair). I also asked the mothers to consider any posture and activity that might be missing. The mothers did not add any new postures or mothering activities.

Coloured stickers, post-it notes and emojis

 Coloured stickers, emojis and post-it notes were also used to explore the mothers' priorities with regard to mothering activities (Figure 4.8). Five colours were provided to show the level of importance of the mothering activities (i.e. orange for extremely important, pink for important, yellow for average, green for not important and blue for not important at all).

Of the thirteen mothering tasks, the mothers could choose any number as being extremely important. They did not have to rank these. Consequently, each mother chose priorities based on her preferences.

Figure 4.8. Coloured stickers, emojis and post-it notes.

The mothers used post-it notes to express their feelings and experiences regarding the mothering tasks. As well as coloured stickers and post-it notes, emojis were offered to the mothers as another way of expressing their feelings and experiences. According to Nakarada-Kordic et al. (2017) emojis can be an effective way to facilitate participants' expressions or feelings in co-design activities. During this part of the co-design session, the mothers explained their reasons for choosing the stickers and emojis. Thus, the emojis and coloured stickers were used to help the mothers thought processes and support them to talk in more detail about their priorities in mothering.

I had prepared a 2D visualisation (A3 size) with photos of the mothering activities that were identified in Cycle I (Figure 4.9). The images of mothering activities were the same as those used in the card sorting activity. The images contained both physical and emotional activities. For example, physical activities included changing a nappy, clothing and feeding a child. The images also included various emotional activities

such as calming a child, having fun with a child, comforting and kissing a child. Prioritising mothering activities helped me to explore how the mothers construct meaningful mothering experiences.

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Figure 4.9. The A3 paper with images of mothering activities to identify mothers' priorities.

The A3 paper with images was placed on a table within easy access for a mother. Usually, the mothers chose a sticker then I pasted it on the sheet for them and the mothers mainly focused on explaining their priorities and experiences. All mothers used a combination of coloured stickers and post-it notes. Four mothers used emojis to express their feelings and experiences about each activity.

Two of the mothers were very interested in using emojis to as the best way for them to express their feelings. They mentioned that emojis were useful to help them clarify the words they were using to describe their thoughts. Two mothers were not interested in using emojis so these two mothers explained their feelings verbally (Figure 4.10).

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Figure 4.10. Using coloured stickers, post-it notes and emojis.

Drawing

Drawing has been demonstrated as an effective way to visualise participants' ideas through co-design (Hussain, 2011; Steen et al., 2011). I offered drawing as a communication tool to explore the mothers' ideas and experiences of mothering through visual language. I offered them paper (A4 size), pens and pencils and gave them the choice whether or not to draw their ideas (Figure 4.11).

Two mothers chose drawing and two mothers did not because of their lack of dexterity. Two of the mothers were not interested in drawing. They preferred to share their ideas verbally instead of visualising ideas.

Figure 4.11. A pen and paper was offered to the mothers for drawing; drawing was used to visualise the mothers' ideas.

Object-making

Object-making was used as another way to facilitate the mothers' ideation and expression to give form and communicate their ideas (Figure 4.12). These ideas were then used and developed in Cycle III to find new opportunities for the mothers. In co-design, making objects plays an important role to explore hidden layers of users' feelings (Sanders & Stappers, 2014).

A variety of materials were offered to the mothers for making objects, including coloured paper, cardboard, dough, straws, sticks, ribbon, cloth and foam. I put all the materials on a table close to the mothers for ease of access. Mothers who were interested in making objects chose the materials based on their interest, then they made their objects. Two of the mothers chose to make objects and four mothers did not. Two of the mothers, due to lack of fine dexterity, did not have the physical ability to make objects. The other two mothers said that they were not interested in making objects. We initially tried to make an object together. For instance, a mother and I chose the material and involved in the process of object-making collaboratively. But after some attempts in object-making the mother preferred to explain her ideas verbally. Thus, I continued to object-making based on her ideas and comments.

Figure 4.12. A mother making an object in the co-design session. Object-making with different materials such as play dough, cardboards and foam was used to give form to the mothers' ideas.

4.2.4 Co-design procedure in Cycle III

In the co-design workshops of Cycle III, findings from Cycle II were summarised and presented back to the mothers. I reviewed my findings regarding the mothers' priorities and meaningful mothering experiences at the beginning of the workshop. This conversation was then used to co-design with the mothers. In addition, looking at the analysed data and reviewing the data helped me to verify the findings. This also help to inform the mothers about the aims of the research, and relationships between the research cycles.

Once again I used generative tools to collect data. In doing so, in the workshops, we undertook different activities to find new opportunities to create meaningful mothering experiences. These activities included sorting cards and concepts, inspiration cards, drawing and making objects as described below (Figure 4.13).

Figure 4.13. Materials in the co-design workshop.

The activities in the workshop were carried out based on the group's choices and interests. Each workshop took approximately two hours (Figure 4.14).

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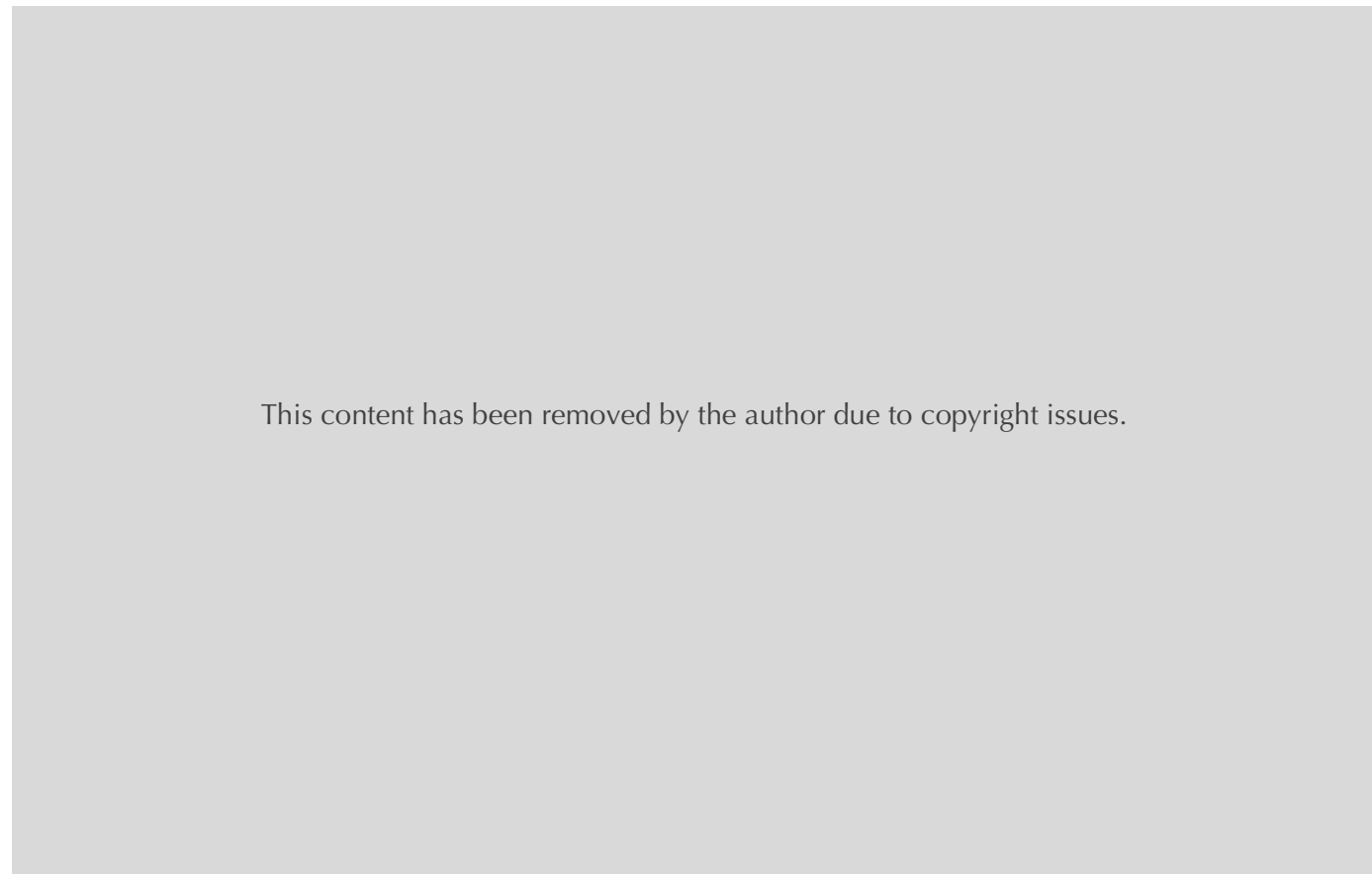
Figure 4.14. Co-design workshop in Cycle III.

Sorting cards and concepts

The aim of the sorting cards and concepts activity was to identify the mothers' viewpoints on the most important characteristics and specifications of 'fit' product/furniture. Cards included seven images of the different types of furniture/ chair (i.e. soft furniture, floor furniture, recliner, armchair and ottoman) commonly found in a home environment (Figure 4.15). Each card was 10 cm x10 cm in size.

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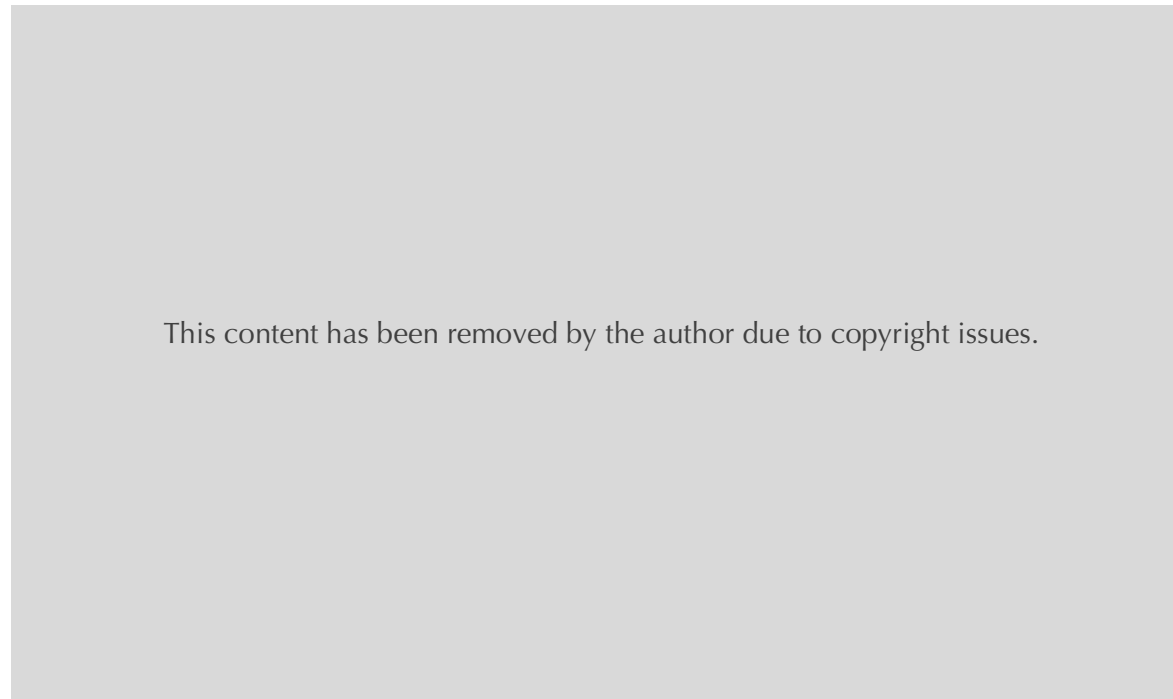
Figure 4.15. Sorting cards, Individual cards showing furniture/ chair. Source: Author's collage of images

I also presented some of my concepts that were inspired by findings of Cycle I and II (Figure 4.16). These concepts were presented on A4 paper and included sketches of wheelchairs with new features, ideas for bathing and child-caring products, and are explained in more detail in Chapter 7.

Figure 4.16. Sorting concepts, Individual papers showing wheelchair, ideas for bathing and child caring products.

Inspiration Cards

Given the role emotion plays in people's perceptions and experiences (Norman, 2004), creating favourable emotions can help move a product from being one that was viewed as being purely functional to one that was also seen as being meaningful.

The aim of inspiration cards was to help identify how the mothers construct meaningful mothering experiences in their home environment. For this activity six inspiration cards were placed on a table within easy access in front of the mothers. Each card was 10cm x 5cm in size (Figure 4.17).

Figure 4.17. Inspiration cards.

Through the inspiration cards, I explored the mothers' dreams, fears and how they constructed the meaning of home. In doing so, I focussed on the following areas:

- Wish and dreams; the mothers described 'What they wish for an accessible product/ furniture';
- Fears; the mothers described 'What they fear regarding mothering';
- Home; the mothers described 'What home means to them' and 'How they like what their home looks like'.

By only using a few words on the cards, I intended to prompt the mothers to describe their experiences, fears and dreams. Essentially, this activity was a combination of cards and sentence completion. They shared their fears and dreams regarding mothering, products/furniture and the home environment. The mothers completed the sentences on the card verbally. This was then used as a prompt to more deeply explore the mothers' thinking around their response.

Drawing

Similar to Cycle II, drawing was used to facilitate communication and idea generation. Three mothers chose drawing for idea generation. As with cycle II, the same two mothers were not interested in drawing, and preferred to explained their ideas verbally.

Object making

Similar to Cycle II, making objects was used as another communication tool. In doing so, the mothers were invited to make objects to give form to their desires and ideas. The toolkits consisted of three pre-made main spaces of home environment including the bathroom (Figure 4.18), the bedroom (Figure 4.19) and the lounge (Figure 4.20). These three spaces were chosen by the mothers as directly relating to their main priorities of mothering activities in Cycle II. I had premade toolkits that contained simple prototypes of objects and visual forms for better communication. The toolkit of 2D

and 3D components was used as a way for the mothers to express their desirable features of 'fit' product/ furniture.

Materials including coloured paper, cardboard, dough, straws, sticks, ribbon, cloth and foam were offered to the mothers. Through this activity, the mothers made and described what they wanted in new products/furniture.

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Figure 4.18. Toolkits containing simple prototypes and visual forms, bathroom.

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Figure 4.19. Toolkits containing simple prototypes and visual forms, bedroom.

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Figure 4.20. Toolkits containing simple prototypes and visual forms, lounge.

4.2.5 Data collection procedure in Cycle IV, Feedback on prototypes

As discussed earlier in this chapter, I used semi-structured interviews in Cycle IV. Given that the aim of Cycle IV was to share the prototypes with the mothers and hear their feedback, I started data collection in this cycle with a presentation of a summary of the findings of previous cycles. I shared the findings using a PowerPoint presentation on my laptop (see Appendix F). Through the PowerPoint slides, I showed the images and renders of the prototypes in the home environment. The slides presentation also included the a summary of the findings from Cycle II and III, which had led to the ideas and concepts behind the prototypes, the animation and image of the prototypes at home environment. Then, we discussed how the prototypes might work. Finally, I invited the mothers to share their feedback on the prototypes and to express their most candid opinions regarding the prototypes.

This was because, the mothers had a key role in creative design solutions and validation of ideas in my research.

Sharing the prototypes with the mothers helped me to explore the ideas from the mothers' perspective. In doing so, I initially asked the mothers about their feedback on the prototypes, and further enquired about the reasons behind their feedback. I also invited them to share their experience and feedback on the co-design sessions in Cycle II and III to explore their perspective on the process of our co-design sessions.

4.3 Data analysis

The section begins with a description of the qualitative analysis approach used to analyse the data. This is followed by a description of the qualitative analysis approach used to code and classify participants' experiences into themes.

Data analysis procedure

The process of data analysis was initiated at the same time as the data was being collected. For each cycle, all the recordings of the interviews and co-design sessions were transcribed verbatim by a transcriptionist. I then checked the accuracy of the transcripts by simultaneously listening to the audio recordings and reading the transcripts, comparing them with notes taken during the interviews and co-design sessions. Following this, the transcripts were emailed to the participants to verify their accuracy (i.e., member checking), to help ensure the trustworthiness of the data and results (Doyle, 2007). The participants received the transcripts via email. No requests were made by them to remove or modify any of their statements or contributions.

Data were analysed applying thematic analysis (Braun & Clarke, 2006) using six stages as follows:

1. familiarising the researcher with gathered data;

2. generating initial codes;

3. searching for themes;

4. reviewing themes;

5. defining and naming themes;

6. providing a final report.

This data analysis process was applied in each of the four research cycles. In order to familiarise myself with the data, I read the transcripts several times and made notes, which I used to help identify the initial codes. This step involved the initial selecting and organising of the data.

To help manage the data, the transcripts were imported to the NVivo Software (QSR International Pty Ltd. Version 12, 2018). The data were initially analysed using NVivo Software, then I decided to manually analyse the codes because through

manual analysis, I was better able to engage with the data and develop my critical thinking towards it, which I found more effective to find links and draw conclusions. I visualised the initial codes by arranging them to create a map showing the common patterns in the data as whole.

Following this, these initial codes were assigned to broader codes. Next, the codes were assigned to candidate themes.[10] In the final step of analysis, the themes were defined and categorised (Braun & Clarke, 2006). By visualising the data I was able to gain a more comprehensive understanding of the themes and patterns that I had identified from the interview data. When visualising the data, the focus was not only on

what each participant had stated separately, but on patterns of participants' common experience in the data as a whole.

The next step involved looking through the analysed data to draw out conclusions to address the main aim of each research cycle. Throughout the analysis (for each research cycle), I revised and verified codes and themes by frequently reviewing the data to check the conclusions that were being made. In doing so, I periodically reviewed visual maps of the initial codes and candidate themes, and looked for new themes, as well as checking the validity of the previously identified themes. This proved to be effective as I became more engaged with the data and the candidate themes. For instance, in Cycle IV, by reviewing the data and the relationships between the

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[10] "[C]andidate themes are developed from the analytic work of the earlier phases, and 'tested out' in relation to the research question/dataset overall. Knowing that not all candidate themes will necessarily survive this early development process is vital to not getting too attached" (Braun et al., 2019, p. 854).

codes and candidate themes, the candidate theme "a 'fit' product as an opportunity to construct meaningful mothering experiences" was subsequently developed to become "from a heart-breaking mothering experience to a ground-breaking mothering experience" as a final theme. The results obtained from the analysis of each cycle informed the aim, direction and focus of the following cycle.

4.4 Conclusion

This chapter has described a detailed description of the research participants, the data collection and analysis procedures. Semi-structured interviews and co-design methods were applied to explore the construction of meaningful mothering experiences through child-caring products in home environment.

The interviews with the mothers in Cycle I, were important to help me frame up how I would approach the co-design activities planned in Cycle II. The individual co-design sessions were applied in Cycle II to better understand the construction of meaningful mothering experiences with SCI based on the mothers' priorities and the products they used in their child caring activities. In Cycle III, through co-design workshops I explored the features and characteristics of 'fit' products. In Cycle IV, I applied semi-structured interviews to hear the mothers' feedback on the prototypes, and our co-design process. This chapter finished with the description of the data analysis procedure.

Chapter 05.

Cycle I: Problem Identification

Introduction

In the first cycle of my research, I explored the mothers' perspectives on those mothering activities they found challenging and also those mothering experiences that they identified as meaningful in their home environment.

According to earlier studies, disabled mothers experienced various physical barriers that made their mothering experiences challenging (e.g., Wint et al. 2016; Mitra et al. 2017; Fritsch, 2017; Powell et al. 2019). Consequently, I had initially assumed the mothers' challenges would affect their construction of meaningful mothering experiences. However, I put aside my previous assumptions to give voice to the mothers through the process of participatory action research. The findings of Cycle I, which are presented here, called into question my assumption about the impact that challenging mothering activities might have on the construction of meaningful mothering experiences for women living with SCI.

In Cycle I, through interviews with the mothers, I explored the following areas:

- What were the mothering activities the mothers found challenging?
- What age and behaviour of a child was more difficult for the mothers and why?
- What were meaningful mothering experiences?

5.1 Challenging activities for the mothers

Findings revealed that for the majority of the mothers, a variety of activities were identified as being challenging. These included a range of physical and emotional tasks associated with mothering. For example, moving to ground level (i.e., changing position from sitting in a wheelchair to sitting on the ground/floor and getting back to a wheelchair), bathing and picking up a child were described as the most difficult tasks by most mothers.

The most difficult period was the time during the first three years of their child's life. This was the period when children needed the most help with many tasks, including being fed, bathed, changed, and dressed. Most young children spend all their time on the ground (i.e., crawling and playing). Thus, the ground or floor was considered by most of the mothers' as an inaccessible area. Findings also showed that the tetraplegic mothers had more difficulties with dexterity which rendered activities such as changing nappies, dressing and bathing even more difficult for them when compared to the paraplegic mothers.

Several mothers described moving to the ground as one of the most challenging activities. This activity usually took a lot of their time and effort:

> "I normally don't reach down to the floor very often […]. Getting me to the floor and back up was one solution and that was still difficult and time and physical consuming." (Sophia)

Another challenging activity for many mothers was bathing a child. The mothers described the action of maintaining their balance as one of the most important issues when bathing a child:

> "Especially when they're new-borns, new-born would've been the hardest. Because you had to have two hands to lift them. I did everything with one hand because of my balance, balance problems. When he was new-born would've been the hardest probably. And reaching over and leaning over I wasn't very good at reaching over and leaning over too far." (Allison)

Allison described bathing her infant as the most difficult task. Allison bathed her infant from her wheelchair. Consequently, she needed to maintain her balance with one hand and bath her child with her other hand. Allison mentioned that holding a new-born's small and floppy body with one hand was challenging.

Several mothers described manoeuvres such as stretching their body and leaning over during bathing an infant from a wheelchair as difficult activities.

Picking up a child was another significant challenge identified by many of the mothers. While this is something which may be taken for granted for many new able-bodied mothers, for those mothers with SCI, new actions or activities such as picking up a child presented many new problems or difficulties to overcome:

> *"So much trial and error, even like how to pick him up when he was an infant. It was just a lot of trial and unfortunately I did drop him a couple of times and luckily I always had blankets around and things like that. […] but trial and error and hearing from other mums that have done it. That was really important." (Rosa)*

The above excerpt highlights there was a lack of practical resources for preparing the mothers in a wheelchair for mothering. For instance, how to pick up a child, how to wheel a wheelchair and hold a child safely, or how to breastfeed and keep their balance were activities the mothers felt they needed to be better prepared for before childbirth. The majority of the mothers acquired ways of coping with their issues through trial and error, which was something most of them emphasised.

Sophia, quoted below, considered that while able-bodied mothers have many role models in the media and family or friends who can familiarise them with tips or techniques for mothering; usually mothers with SCI do not have such role models:

> *"Most non-disabled women had so many role models of how to be a good mother but as a young disabled woman, you don't see any role model whatsoever." (Sophia).*

Lack of disabled role models can highlight the normative approach (Garland Thomson, 2011) to mothering. As shown by Sophia, disabled role models are invisible in society and media. Thus, the advice and methods which would be

beneficial for the majority of able-bodied mothers do not 'fit' disabled mothers' needs. This can imply that mothers with SCI are in the shadow of able-bodied mothers and their needs and ways of mothering are not accounted for and they needed to find their own ways of performing mothering tasks.

Similarly, all of the mothers reported a lack of access to child-caring products that met their unique situation. While there are a very limited number and range of globally available products considered 'fit' for use by disabled mothers, access to these is even more limited in Aotearoa New Zealand. Most of the mothers had difficulty finding locally available child-caring products to address their needs. The absence of 'fit' child-caring products resulted in them often needing to modify existing products in order for their specific needs to be met. A typical response to a query regarding the use of child-caring products went as follows:

"I have to do a lot of adapting. I had to find things that were in the market and adapt it. So a cot, the

bassinet was ok but a cot, we had to get that modified. I used a sling, then I tried a front pack." *(Allison)*

In addition, as a consequence of the lack of 'fit' products, the mothers applied creative strategies to modify existing products to address their needs. For example, wheeling a wheelchair while holding a child was frequently described as one of the mothers' main challenges. The majority of the mothers explained that they carried their child on their knees and held their child with one hand while using their other hand to wheel their wheelchair. This limited a mother's ability to use both hands to wheel her wheelchair to move around. One of the mothers described how she used a weightlifter's belt for carrying a child while wheeling her wheelchair. The weightlifter belt assisted Emma to hold her child 'hands free' and safety while riding her wheelchair. Consequently, Emma no longer needed to use one hand to carry a child and wheel her wheelchair using the other.

"Something that annoyed me was trying to wheel and hold a child. But in the end I got a weightlifter's belts. I got one of those, big Velcro and I put around me and put around her." (Emma)

The majority of the mothers modified their child's clothing such as pants and overalls to make it possible for them to pick up their child from the ground. For example, some mothers reported that they sewed material onto the back of their child's clothing for the purpose of creating a kind of handle to more easily lift their child from the floor

"We did adapt our children's clothing, we could grab them with one hand. Like those handle from the shoppers that lifts up like a handbag." (Allison)

The mothers' resourceful solutions highlight how the normative approach of catering for parents who are able-bodied and have fine motor skills influence product design and lead to marginalisation of minority groups such as mothers with SCI. As a result, the mothers' applied creative solutions to fit themselves to the material environment.

During the interviews, some of the mothers used their photographs of the cot, changing table and baby carrier to help describe their mothering experiences in more depth. The mothers showed me how they modified products. In the main, products such as furniture tended to be modified (such as beds, cots and change tables). All the modifications were done by the mothers' family or friends. In two cases, the mothers had been given modified furniture from other mothers with SCI who no longer needed them. One of the mothers modified a bed for her child (Figure 5.1). Lily had designed a bed door on a vertical axis with locks for her child safety, thus, there was enough room under the bed to access it from her wheelchair. This helped Lily to maintain her balance and when she went to lift her child in or out of the bed, while she

was in her wheelchair. The majority of the mothers modified

beds to meet the mothers' needs including the ability to roll

beneath a bed to pick or put down an infant.

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Figure 5.1. A sample of the mothers' 'home-made' modified products, A baby bed,
Source: The mothers' photograph.

Lily also used a modified changing table. This allowed her to manoeuvre her wheelchair under the table and more easily change her child's nappy (Figure 5.2).

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Figure 5.2. A sample of the mothers' 'home-made' modified products, A changing table, Source: The mothers' photograph.

Two mothers had made a baby carrier, in order to carry a baby in their wheelchair. One of the mothers used a baby carrier which was attached to a wheelchair to hold her child (Figure 5.3). Again, this product was made by her friend. This baby carrier allowed the mother to wheel her wheelchair with her both hands, and carry her baby safely.

Given that this baby carrier was used for an infant under three months, the infant's weight could not cause an imbalance of a mother's wheelchair. The baby carrier was attached to a mother's wheelchair by metal fasteners. The baby carrier was made of water-resistant cloth.

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Figure 5.3. A sample of the mothers' 'homemade' modified products, A baby carrier for an infant under three months that attaches to a mother's wheelchair, Source: The mothers' photograph.

Another mother made a baby carrier suitable for a baby aged over six months (Figure 5.4). The baby carrier was made of water-resistant cloth and metal fasteners. The metal fasteners were used to attach the carrier to a mother's wheelchair.

Given this baby carrier did not require a mother to protect a child with her hand, the mother could use both her hands to wheel her wheelchair. There were open spaces around the carrier for air circulation for the ease of putting the baby into it and to mitigate perspiration.

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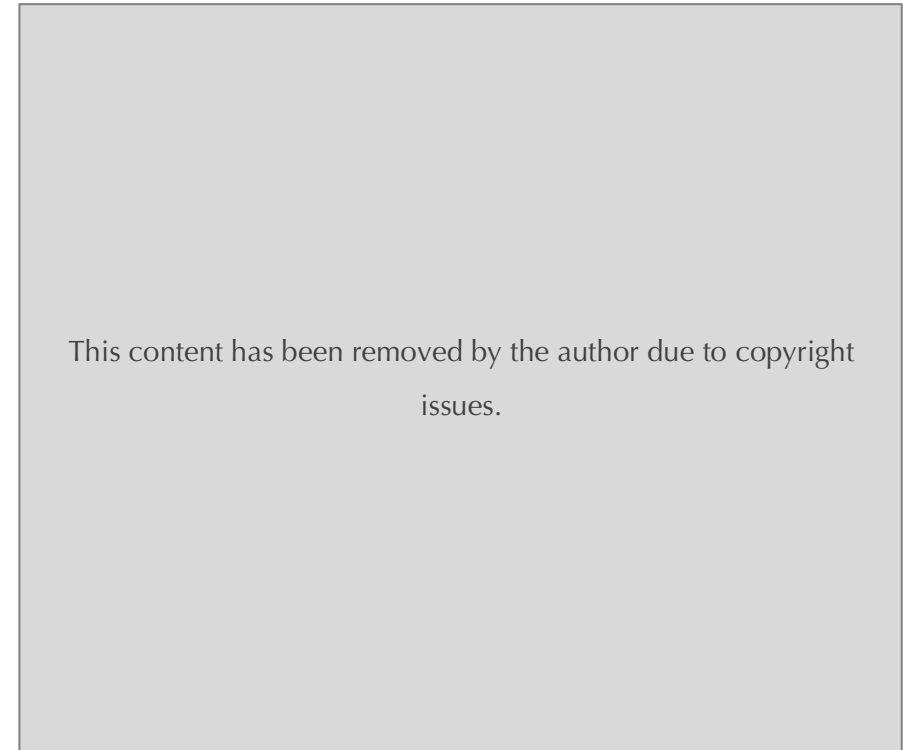
Figure 5.4. A sample of the mothers' 'homemade' modified products. A baby carrier for a baby aged over 6 months that attaches to a mother' wheelchair. Source: The mothers' photograph.

The mothers' modified/ invented products indicate how child-caring products, which address the mother' needs can help facilitate mothering tasks and enhance their engagement with their child. For instance, a baby carrier which fitted the mother's need not only assisted a mother to easily and safely move around but also provided a mother with an opportunity to become more engaged with her child.

While the majority of the mothers mentioned that modification of child-caring products was necessary to facilitate their mothering activities, they also expressed frustration over the lack of availability of child-caring products to meet their needs. In cases where there was no modified child-caring product, the mothers had to rely on a third party[11] for mothering activities. The impact of relying on a third party on the construction of meaningful mothering experiences was

explored further and is discussed in depth in Cycle II (see section 6.3) and Cycle III (see section 7.1).

The findings highlight the impact of lack of child-caring products in the market for mothers with SCI in Aotearoa New Zealand. Therefore, mothers with SCI (i.e., their family or friend) had modified or designed child-caring products such as a baby carrier for carrying a child in a wheelchair. The findings also highlight that child-caring products have been primarily designed based on able-bodied caregivers. One could therefore argue from these Cycle I findings, that the consequences of product design based on able-bodied people could be more disabling than the physical impact of spinal cord injury. Moreover, the lack of child-caring products that fit the needs of the mothers can limit their ability to undertake mothering tasks such as changing nappies, carrying a child

[11] In this research a third party refers to any person who helps a mother in performing mothering activities including a mother's caregiver, support worker, partner, family or friend.

safely in a wheelchair or spending one-on-one time with their child. Such limitations can, therefore, impact on the construction of meaningful experiences, which was explored further in Cycles II and III.

5.2 Meaningful mothering experiences

The analysis of data from Cycle I provided me with initial insights into the construction of meaningful mothering experiences. These findings highlighted how meaningful experiences are constructed through the mother-child relationship. According to the analysed data, carrying out mothering tasks helped to create a repeated exposure and interaction between the mother to her child. These were perceived by the mothers to build up their mother-child relationship. This relationship is important for a mother and a child. As Bowlby stated (1951), "the infant and young child should experience a warm, intimate, and continuous relationship with his mother (or permanent mother substitute) in which both find satisfaction and enjoyment" (p. 13). The majority of the mothers emphasised their intimate mother-child relationship as meaningful mothering experiences. For instance,

> *"When Jack got older and like sitting in a high chair, he and I were the same level. We sat next to each other and I would feed him so that was one of the things that I could do because we were at the same level and he could sit facing me and I could use the spoon and feed him and so lots of that kind of stuff was gorgeous." (Hannah)*

> *"[Being a mother] is my favourite thing in my whole life because it's so honest and real and a time in a world where so much is fake and instant and insincere being a mother is the opposite to that." (Sophia)*

From the mothers' viewpoint, a meaningful mothering experience represented a connection that a mother make with her child. Mothering tasks were not only physical tasks, but also a way of expressing their love for their child. Cycle I revealed meaningful experiences were those that went beyond physical tasks to create a more emotional experience.

Although the intimate mother-child relationship played a key role in the construction of meaningful mothering experiences, the findings also revealed the impact of societal attitudes on its construction. On one hand, the material environment did not fit the physical needs of the mothers, while on the other hand, society expected the mothers to fit themselves to stereotypes of an able-bodied mother. Moreover, the findings showed how the mothers with SCI constructed their mothering world, and how the influence of the social construction of a 'good mother' impacted them.

For several mothers, the 'act of mothering' was associated with being able to do mothering tasks without help. For instance, In their 'perfect world' a mother was described as a person who can do mothering tasks and attend to a child's needs:

> "In my perfect world, I'd be getting her dressed and driving her to school without anyone's help. When she was a baby, I wanted to be the one who jumped out in the middle of the night to grab her when she cried. We would travel alone to the

> beach together and I'd be the one to teach her how to swim." (Stella)

From Stella's perspective mothering consisted of various tasks, including physical tasks such as dressing her child, emotional tasks such as comforting her child and social tasks such as teaching her child about the world. The majority of the mothers were eager to do all the mothering tasks by themselves, without asking for help.

Olivia described how asking for help with mothering tasks was 'the most difficult' aspect of mothering with a spinal cord injury:

> "I don't want to need any help but I need help so and that's the part, that's the most difficult about being having a spinal cord injury and then having young kids because the support workers are effectively parenting the children. Because you don't have the hand function or you don't have the physicality to be able to do all the things that you want to be able to do as a mum." (Olivia)

The above excerpt highlights that the level of spinal cord injury and the age of a child affected how Olivia constructed meaningful experiences. Olivia, as a tetraplegic mother living with a higher level of injury and a younger child (i.e. under three years old), had to rely on a third party more than a paraplegic mother would need to. Consequently, a third party who could physically do all the mothering tasks on behalf of Olivia appeared to threaten the mother-child relationship by 'breaking the bond' between Olivia and her child.

In her interview, Olivia considered activities such as cooking, changing nappies and feeding her children as the tasks which were supposed to be performed by her as the child's mother. The way she described these tasks suggested how the stereotypical expectation of being a 'good mother' can affect the construction of meaningful mothering experiences with SCI. Thus, the 'act of mothering' without relying on a third party was considered as the 'real' way of mothering. Consequently, for the majority of the mothers, having to rely on a third party produced a sense of heartbreak as well as 'being an observer':

> *"You're basically an observer with a spinal cord, you're an observer to your life as a mother. You're watching other people mother your children. […] you were unable to do the things that you desperately wanted to do and it just breaks your heart. It's heart-breaking." (Olivia)*

When the notion of being a mother appears to be defined by the ability to perform the mothering tasks independently, then it can influence the way the mothers construct their mothering experiences:

> *"I started to feel more like their mum when there wasn't a third party involved in our relationship." (Olivia)*

In addition, my findings reveal the discriminatory approach toward mothering with SCI affected mothering experiences. The interviews suggested that the social construction of an able-bodied mother resulted in a mother's social exclusion:

"I think with these fears in our head a big one is when out in public with my son. So for a long time, I wouldn't take him out in public. [….] That was really challenging, the fear of other people. And them judging me for not being a good mother and them thinking how on earth does she think she's going to be a mother if she's in a wheelchair? and I think that's a big thing for people with spinal cord injury is that it's not so much this independence, it's this idea that people are perceiving that you can't do it by yourself and that you need help. And that is really difficult." (Rosa)

The excerpts above opened my eyes to the significant role of societal attitudes in the construction of mothering experiences with SCI. Rose's experience indicated that other people's judgment made her feel that she had to prove her mothering capability. This shows how the impact of the social construction of an able-bodied mother could reinforce discriminatory attitudes and behaviours towards the mothers with SCI. The societal attitudes and continual judgemental scrutiny towards a mother with SCI led her to feel insecure in the public eye and consequently forced her to limit her activities in public places. Thus, societal attitude can narrow a mother's world to become smaller than an able-bodied mother.

5.3 Conclusion

The findings of Cycle I provided me with an initial insight into the construction of meaningful mothering experiences with SCI. According to data analysis based on the priority of needs, the similarity of needs and the chance of finding designable solutions, four specific activities of mothering in a home environment were chosen for further exploration. These mothering activities included moving to the ground level (i.e., changing position from sitting in a wheelchair to sitting on the ground/floor and getting back to a wheelchair), bathing, wheeling, and carrying a child, and picking up a child. The findings of Cycle I also indicated the most challenging period for the mothers was during the first three years of their child's life.

The data gathered from the mothers influenced what I focused on during the subsequent codesign sessions; thus, the mothers' perspective also guided my questions for the next cycle. Furthermore, the findings challenged my assumptions regarding the mothers' priority of mothering tasks and what they considered meaningful mothering experiences. While I intended to focus on those challenging activities for the mothers and explore possibilities to help better facilitate these challenging tasks, after data analysis, I came to understand there was a difference between a mother's physical challenging activity and what they considered a meaningful mothering experience. I had assumed the activities that the mothers had more difficulty doing for their child would impact on their experiences of mothering. I had thought the level of challenges and difficulties would be an indicator to identify meaningful experiences. However, the findings show the amount of bonding and intimacy that was created through the mothering tasks was the most important factor for the mothers to construct meaningful experiences. This was further explored and clarified in Cycle II.

Chapter 06.
Cycle II: Deeper understanding

Introduction

In Cycle I, I found that from the mothers' perspective there was a difference between what consisted of a challenging mothering activity and a meaningful mothering experience. Although the mothers were eager to do all the mothering activities by themselves, the findings from the first cycle indicated some activities were more important to them than others. In the second cycle, I explored the mothers' priorities regarding mothering activities to gain a better understanding of how mothers constructed meaningful experiences in relation to their mothering.

In this second cycle of my research, co-design sessions with the mothers were used to gain a deeper understanding of how the mothers construct meaningful experiences by exploring the key findings from Cycle I in greater depth. Consequently, in Cycle II, I focused on asking the following questions:

- What were the mothers' main priorities in mothering activities?
- What was the relationship between being a mother and mothering activities?
- What were the mothers' views about relying on a third party in mothering activities?

6.1 The mothers' priorities in mothering activities

Through the individual co-design sessions, the mothers shared their experiences, concerns and priorities regarding their mothering activities. In analysing the data, mothering tasks were categorised into three main groups: bonding; spending time with a child; physical activities (see Table 6.1).

All of the mothers described the bonding category tasks as the most important group of mothering tasks. The bonding category included breastfeeding, having physical proximity, calming a child, kissing and cuddling.

Table 6.1. The mothers' priority in mothering tasks, the orange colour indicates the most challenging activity in each category.

Mothering Tasks		The most challenging activities	The mothers' priority
Bonding	Breastfeeding	🟧	The first priority
	Kissing & cuddling		
	Calming a child		
	Physical proximity		
Spending time with a child (playing on the ground, drawing, creative activities)	Sitting on the ground (moving onto the ground/floor)	🟧	The second priority
	Sitting around a table and doing creative activities		
	Drawing		
Physical activities	Bathing	🟧	The third priority
	Feeding		
	Changing a nappy	🟧	
	Bedtime		

In addition to their priorities regarding mothering activities, the mothers also expressed their views on what they identified to be the most challenging activities. They described changing a nappy, bathing, sitting on the ground and breastfeeding as the most challenging activities to perform.

The most important group of activities for all the mothers was those which built an attachment to their child. Findings highlighted the significance of developing a unique emotional connection with their child. Having physical proximity through activities such as cuddling, and touch helped create and maintain this intimate bond with their child.

> "They (children) have to know they're loved and touched. And touch and eye contact and stories and just hanging out is what makes you special to each other." (Olivia)

From Olivia's perspective physical proximity, eye contact and spending time with her children were considered important for her to develop the bond between her children and herself: 'to be loved and loving'. From her perspective, it was a way to express her love to her children and also to receive their love. As such, the intimate relationship between a mother and her child was constructed as a meaningful experience by most of the mothers.

Playing and spending time with their child was the mothers' next priority. This included drawing and creative activities, many of which often occurred at floor or ground level. The floor was described by most participants as a 'difficult space' to spend time with their child. The mothers also described how children were often at ground level in the first three years of their life, and described the difficulty they had sitting on the floor, and how this affected their engagement with their child. This was described as both challenging and frustrating by the mothers:

> "So play is really difficult because the kids are down at ground level and so you want to be able to engage with them with their toys because they usually they're toddlers they're sitting on the

ground and so that's a very difficult space."
(Olivia)

*"It [sitting on the floor] was more of a fantasy. And
so, if I was in my chair, I'd kind of have like my
legs would have to go out and then the chair
would have to go down. Be pretty cool."*
(Hannah)

Hannah's 'fantasy' was to be able to sit on the floor with her
child. Sitting on the floor provided her with an opportunity to
engage and play with her child. All the mothers emphasised
their young children spent most of their time on the floor; the
area which was inaccessible for the majority of mothers with
SCI. An 'Inaccessible floor' made the act of sitting and
engaging with their child on the floor a desired activity for
several mothers.

The third group of priority activities for the mothers' was
physical activities. This category included activities such as
changing nappies, clothing, feeding, bathing and putting the
child to bed. From the mothers' perspective, this group of
physical activities was considered as less important in
comparison to the other groups:

*"Actually for me the physical tasks of changing
nappies I mean they are just a physical necessity.
So someone can do that, that's not me. So a
support worker[12] can do that and I don't feel like
to me it's not important." (Olivia)*

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[12] According to the mothers, a support worker's role was to provide
physical support to help mothers facilitate mothering activities, including
changing a child's nappies, feeding and clothing a child.

ACC provides supports for people with continuous injuries such as people
with spinal cord injury. To do so, ACC uses independent assessors to
identify an individual's injury and circumstances for support. ACC helps
injured people with support workers to assist them in personal care tasks
(e.g., showering, eating), household tasks and childcare. ACC also pays
weekly compensation for people who cannot work as a result of their
injury. (Ministry of Social Development, 2021; ACC, 2021).

Similar to Olivia, several other mothers mentioned they preferred to focus on other tasks that they could do, not being able to change their child's nappy did not necessarily disqualify them as mothers. For instance:

> "I tend to focus more on what I can do. And so, changing a nappy, didn't matter. […] It didn't, it doesn't reflect on mothering, the ability to change a nappy, in my mind. […] the bonding, I just that's the basis, that's what mothering is. It's the bonding it's the love it's the trust it's the attachment." (Hannah)

According to Hannah, physical activities such as changing nappies were less important compared with bonding activities. This was because, the activity of changing nappies did not impact on the way she connected emotionally with her child.

Consequently, she preferred to focus on those activities that lead to developing intimacy with her child.

The mothers' priorities highlighted how from the mothers' perspectives, the notion of a mothering activity was not only about addressing a child's physical needs, but it was also a way for the mothers to build an intimate bond with their child.

6.2 A mothering task is a love language.

Findings show that while all the mothers desired to do all the mothering activities by themselves, the mothering tasks that were more relevant to the mother-child relationship were given greater priority by them, compared to physical tasks. According to Bowlby (1951), the mother-child relationship refers to the emotional attachment between a mother (primary caregiver) and a child. The findings of Cycle II confirmed the importance of the mother-child relationship to the mothers.

Thus, from the mothers' viewpoint, a mothering task was something more than a just physical task; it was considered a love language:

> "[…] feeding the bubba or getting them dressed or washing them because there's an opportunity for like eye to eye and body contact but that's the only part of that task that is important. It's just the opportunity for bonding. So it all comes back all those tasks have a bonding element to them. But it's not the task itself. So if someone else were to change my bubba's nappy that's fine. Because I'm going to be looking at my bubby eye to eye while that's happening. You know so we're emotionally bonding while someone else is physically doing that job." (Olivia)

While Olivia could not always be physically involved in the process of physical tasks, such as changing nappies, maintaining eye contact while others carried out the tasks allowed her to remain involved in the process. In this way, other activities such as feeding and dressing a child were perceived as opportunities to create more moments for mother-child bonding. The excerpt above highlights how Olivia viewed a mothering activity as an opportunity that made an emotional connection with her child.

Breastfeeding was one of the activities described as being closely tied to mother-child bonding. However, the majority of mothers had experienced difficulty with breastfeeding. This was due to a number of reasons, such as lack of milk, maintaining balance while carrying out breastfeeding, a child having reflux or difficulty with holding a child. Although some mothers considered breastfeeding to be a frustrating and difficult experience, all the mothers considered it to be extremely important:

> "[I] found it very difficult to breastfeed again that was balance, holding the baby, being comfortable that was very difficult. I also wasn't really able to because I didn't have [milk]." (Anna)

> "I think that this [breastfeeding] is the most critical thing for a bubba to bond with their mother." (Sophia)

Several mothers considered breastfeeding a meaningful experience:

> *"100% only mum can do this. No robot, no equipment, no daddy, no nanny no one."* (Sophia)

> *"Cos to me that's one of the closest bonds that I think a mum and a baby can have. Is the breastfeeding so important, it's really great for the relationship between mum and baby, it's a comfort it's their attachment."* (Hannah)

For the majority of mothers breastfeeding was something 'only' mothers could do. Furthermore, breastfeeding was not just an act of feeding, but played an important role in building mother-child bonding. For them, breastfeeding created an opportunity for a mother to connect with her child intimately and frequently. The frequent mother-child interaction and skin to skin contact during this 'most natural' activity, constructed breastfeeding especially as a meaningful experience for the mothers. This frequent interaction provided a mother and her

child with an opportunity to build the mother-child relationship According to my findings, emotional activities that provided mothers with an opportunity to have physical proximity and one-on-one engagement with her child were perceived as activities that built mother-child relationships.

The findings of Cycle I indicated the involvement of a third party in the care of one's child could affect the construction of meaningful mothering experiences. I explored this further in Cycle II. The analysis of the co-design workshops highlighted that the repeated and consistent ability to perform mothering activities was believed by the mothers to be critical to creating a relationship and a bond between a mother and her child. Although the mothers' caregivers would often facilitate mothering tasks, from the mothers' perspective, having to rely on a third party to perform these activities was perceived as a potential threat to the bond between a mother and her child:

> *"It felt like everything had been stolen and I would be replaced […] I need to love her and nurture*

her. So my support worker's role is to facilitate my role as a mother, not to take over my role." (Olivia)

In addition, the permanent presence of a third party and a sense of being 'monitored' was reported as being annoying for several mothers. Consequently, being left alone with a child was described as 'freedom' from a 'third pair of eyes':

"the first time that happened [we went away by ourselves without anybody's help] my heart was like ah there's nobody with us and nobody monitoring my conversations with my kids and you know just freedom from a third pair of eyes." (Olivia)

This excerpt highlighted for me how the permanent presence of a third party was perceived as a continual monitoring and 'judging' of a mother's ability. This could affect the way Olivia perceived her mothering; making her feel that she had to prove her capability as a 'real' mother.

Cycle II confirmed the findings of Cycle I regarding the importance of one-on-one engagement with their child for the mothers. Several mothers considered the limited opportunities they had to interact with their child. For instance:

"There's only small windows in there for that opportunity to touch and engage with your baby." (Olivia)

On the other hand, some mothers tried to find other alternative way to engage with their children:

"I spent a lot of time just holding him, particularly against my skin. So, I would hold him against my skin and that was the bonding for us and yeah that was lovely." (Hannah)

Hannah described that when her child was born, she cuddled him in her arms for long periods of time to increase physical proximity with her child. Given Hannah had limited opportunities to have one-on-one engagement with her child without the presence of a third party, this excerpt could imply

Hannah's attempt to create an opportunity to have a one-on-one interaction with her child.

6.3 Using a product instead of relying on a third party

The findings of Cycle II shed further light on the mothers' strong interest in using a product instead of needing to rely on a third party. The majority of mothers considered that using a product could create new opportunities for bonding, interaction and engagement with their child. For example, in the co-design session, Sophia drew a wheelchair with a foldable base.

The drawing was an attempt to 'give form' to a wheelchair concept to assist a mother to reach the ground level independently, without needing a third party to sit on the ground. Additionally, from Sophia's perspective, being able to sit on the ground would create an opportunity for her to have one-on-one interaction with her child without the presence of a third party (Figure 6.1).
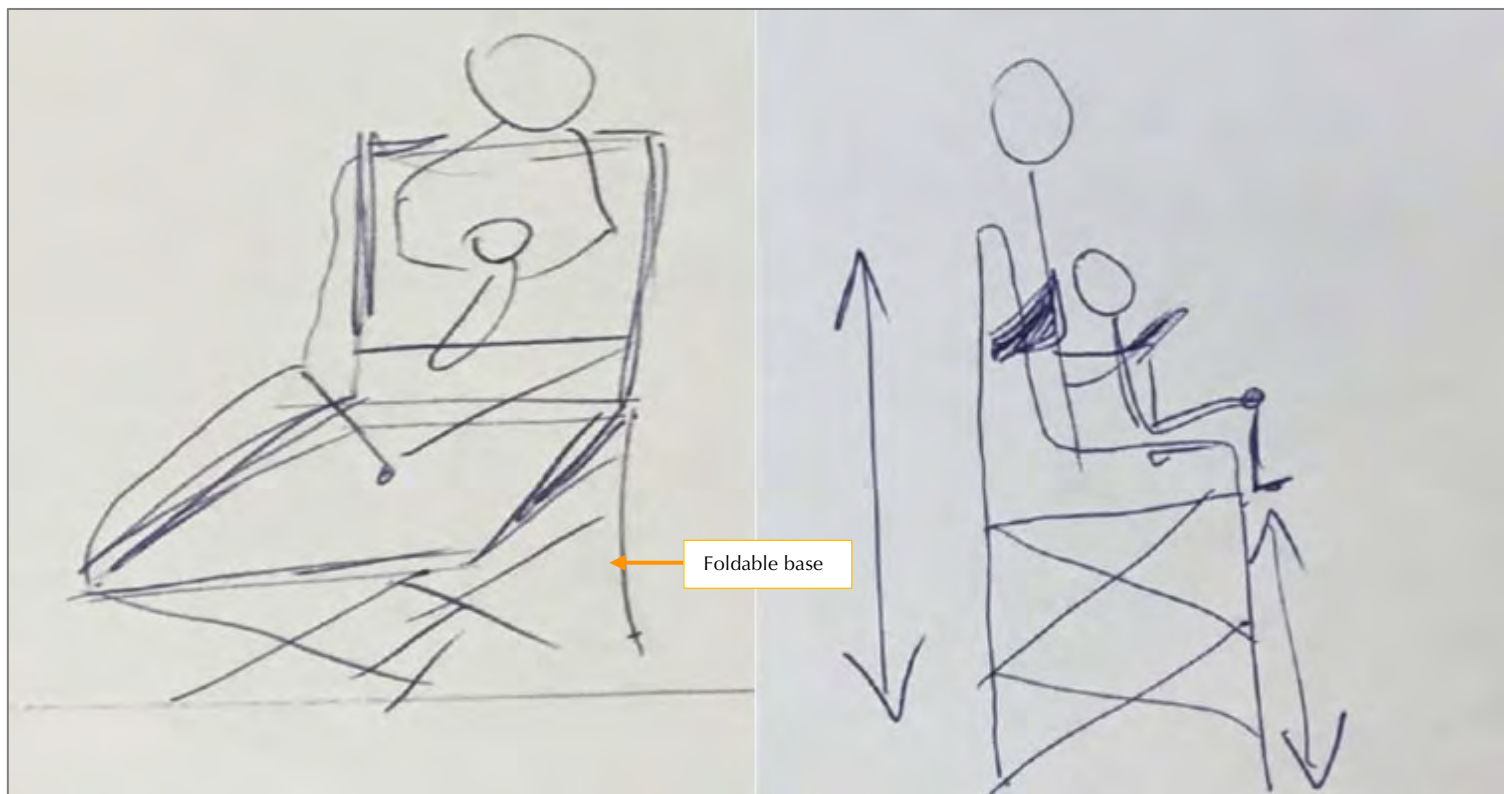
Figure 6.1. Sophia's drawings were a wheelchair with a foldable base that helps a mother to go down the ground.

Figure 6.2. Sophia's object was a wheelchair with a foldable base and a leg rest to support legs.

Wheelchair seat

Adjustable height

To support legs

ability to go down to the ground, without asking help, would enable her to engage with her child more often. Through her idea, she sought a space to develop an intimate and frequent relationship with her child.

The majority of mothers considered having more one-on-one engagement with their child was the main reason for their interest in using a product instead of relying on a third party

> *"I was really glad that I had the equipment that I could kick the help out and have even ten, fifteen minutes of personal sacred time with my baby."* (Sophia)

However, the findings also indicated that using a product would not only create new opportunities to engage with their child, but would also help them to undertake more mothering activities 'as a real mother'. This shed light on how the social construction of a good mother, and the traces of perfectionism in the conceptualisation of motherhood could impact the experience of mothering.

Several mothers compared their mothering to what they observed with able-bodied mothers' way of mothering. It seemed people's judgment and the social construction of an able-bodied mother, as a 'real mother', shaped the way the mothers constructed their mothering:

> *"It [product] would mean that I could do it all myself and look after my daughter as a mother should."* (Emma)

For Emma, her injury prevented her from looking after her daughter as an able-bodied mother would. For example, by playing with her child on the ground, picking her child up from the ground and bathing her child (without needing help). According to Emma, a product would assist her with mothering tasks without needing to rely on a third party. This was similar to the dominant way of able-bodied mothers who can perform mothering tasks independently. Similarly, to Emma, Anna considered removing the sense of herself being a burden on people who helped her (i.e., her family and support worker) as a reason to use a product rather than relying on a third party:

"it's the sense of achievement it's doing it yourself it's being able to do it. Plus, you don't want to be a burden and also there would be there might not be people who can come in to help you." (Anna)

The mothers' interest in using a product instead of relying on a third party opened a new window in my research to find new opportunities for the mothers to engage with their children. While the focus of my research was initially on child-caring products, these findings changed my focus away from only looking at child-caring products. As a consequence, I broadened my focus to include any piece of furniture or product in the home environment that would help facilitate mothering activities. This is developed and described further in the next research cycle.

6.4 Conclusion

The findings from Cycle I were used to inform the research approach in Cycle II, where a co-design process was used to gain a deeper understanding about the mothers' priorities and their construction of meaningful mothering experiences.

Findings showed that while being able to perform mothering tasks was very important for all the mothers, the most important activities were those that were directly related to building mother-child bonding, such as physical proximity, breastfeeding, calming a child, kissing and cuddling a child. The findings of Cycle II highlighted that from the mothers' perspectives, a mothering activity was not only a physical task but also considered to be a love language. However, the need to rely on a third party to perform mothering activities was perceived to threaten the bond between a mother and her child. As a consequence, all the mothers in Cycle II expressed an interest in using a product as an alternative to relying on a third party when undertaking their mothering activities. The analysis of data also revealed the impact of the social construction of an able-bodied mother on their interest in using a product, instead of relying on a third party.

The mothers' interest in using a product changed my initial focus from concentrating solely on child-caring products, to include any product in the home environment that could help build mothers' love language. This was further explored in Cycle III.

Chapter 07.

Cycle III: Finding new opportunities

Introduction

Findings from Cycles I and II highlighted that bonding and intimacy built through mothering tasks were constructed as meaningful experiences by the mothers. In addition, the findings of Cycle II showed how having to rely on a third party impacted the construction of meaningful mothering experiences due to the limited opportunities for a mother to have one on one engagement with her child. According to the findings of Cycle II, all the mothers preferred to use products to assist them instead of relying on a third party in their mothering activities.

The aim of Cycle III was to explore how a product that met the mothers' needs might create new opportunities to construct meaningful experiences for the mothers in their home environment.

In this third research cycle, I set out to explore the following areas:

- What are the most important characteristics and specifications of a 'fit' product/ furniture that would construct meaningful mothering experiences in their home environment?
- How would a product/furniture enhance opportunities to engage with a child?
- What does 'home' mean to the mothers?

The findings of Cycle III are presented in two sections. In section 7.1, I describe the mothers' perspective on 'fit' products as a new opportunity to construct meaningful experiences. Then, in section 7.2, I discuss the mothers' perspectives on the meaning of home. Finally, in section 7.3, I present my design response to the research findings.

7.1 A 'fit' product as a new opportunity to construct meaningful mothering experiences

In Cycle III, I used co-design and generative tools to explore the mothers' perspectives on those characteristics that made products 'fit' for mothering in a wheelchair. During co-design workshops, the mothers shared their ideas and dreams.

In our workshops, we focused on giving form to the mothers' dreams and developing design solutions. This process provided me with an opportunity to step beyond the obvious solutions and uncover unmet needs of the mothers. Drawing was one of the tools we used in co-designing to explore new ideas or view the same ideas from different perspectives. For example, Lily proposed an adaptive tray for different purposes such as changing nappies, carrying and feeding a child. The tray attached to a mother's wheelchair (Figure 7.1).
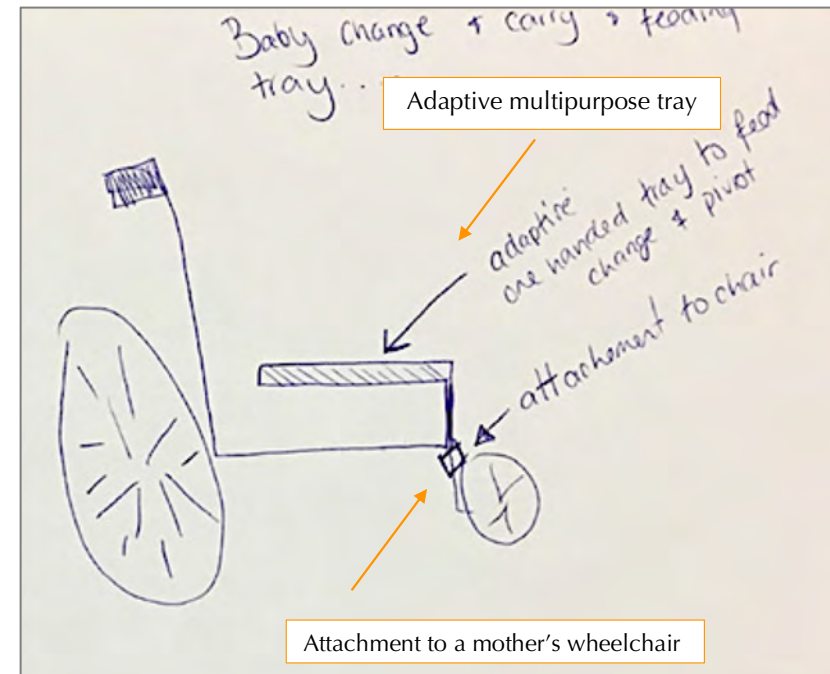
Figure 7.1. Lily's drawing showing a multipurpose tray that attached to a mother's wheelchair.

The other mothers added more features to Lily's idea including a one-handed tray which was lightweight with a pivotal joint (Figure 7.2). During these co-design activities, the mothers' participation played a useful role in the development of ideas in the workshop by adding detail and ideas to each other's concepts.
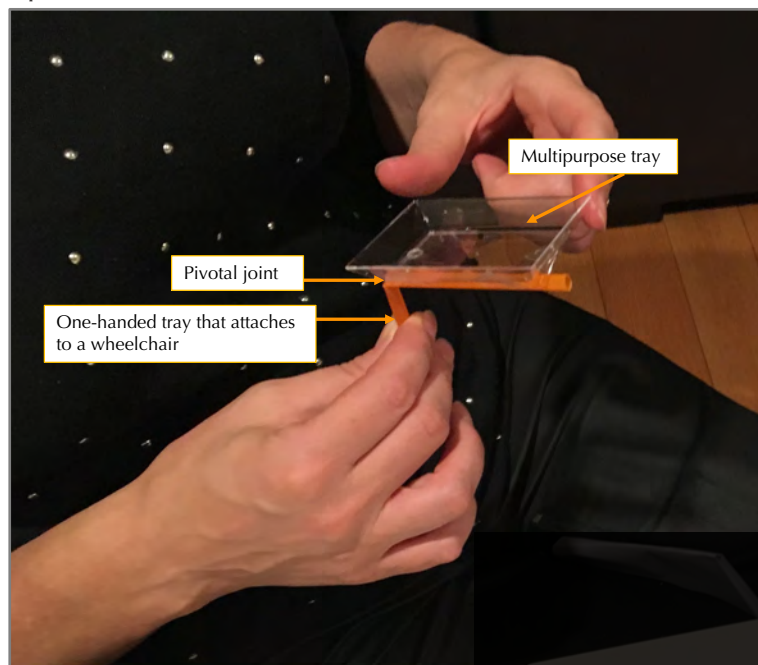
Figure 7.2. Object-making by Lily, a multipurpose tray that attached to a wheelchair for carrying or feeding a child.

The proposal of adding further components to wheelchairs resulted in a discussion about the mothers' relationships to their wheelchairs. For example, the mothers mentioned everybody's wheelchair was different, and their wheelchair could be compared to the concept of their favourite pair of shoes.

All the mothers considered a new wheelchair to be a big change, especially where new mothers were concerned. They also expressed the feeling that attachments (such as a tray) to a mother's existing wheelchair would be more useful than providing a new wheelchair specifically designed to facilitate mothering tasks. Consequently, some mothers considered they **would have liked** to use some wheelchair attachments, such as Lily's concept, to facilitate their mothering activities.

Simple products such as a table to hold or carry items in a wheelchair were described as life-changing products. The most important specifications of these products were mainly centred around the requirements to be lightweight, simple to

use and able to facilitate the mothers' daily living activities. Out of the five mothers, only Hannah had a tray which she used solely to hold her cup and notebook during her meetings at work. While Hannah expressed her satisfaction with using the tray, in practice, she did not use it in ways which might assist her mothering activities. This could have been due to the small tray size which made it suitable only for small-sized objects such as holding a cup or a notebook.

Furthermore, in the third cycle, all the mothers considered many child-caring products to be temporary products. The majority of the mothers made statements similar to the following:

> *"All of these products need to be temporary but long-term temporary because you might have them for three or four years." (Lily)*

> *"From the funding point, I do believe in just hiring them." (Allison)*

According to the findings, there is an opportunity for a product service system such as a 'product library' to facilitate the mothers' access to products which meet their needs. A product library could be a centralised service which allows families to borrow child-caring products such as a cot and baby carrier (see section 9.4).

Through drawing, Allison described the difficulties she had when picking up her child. She drew a baby cocoon with long handles, as an idea to help her pick up her child. She mentioned that a baby cocoon could be used to carry a child in a wheelchair as well. She also thought the long handles would go around her neck to hold a child safely (Figure 7.3).

A baby cocoon with long handles to pick up a child and hold a child safely in her wheelchair.
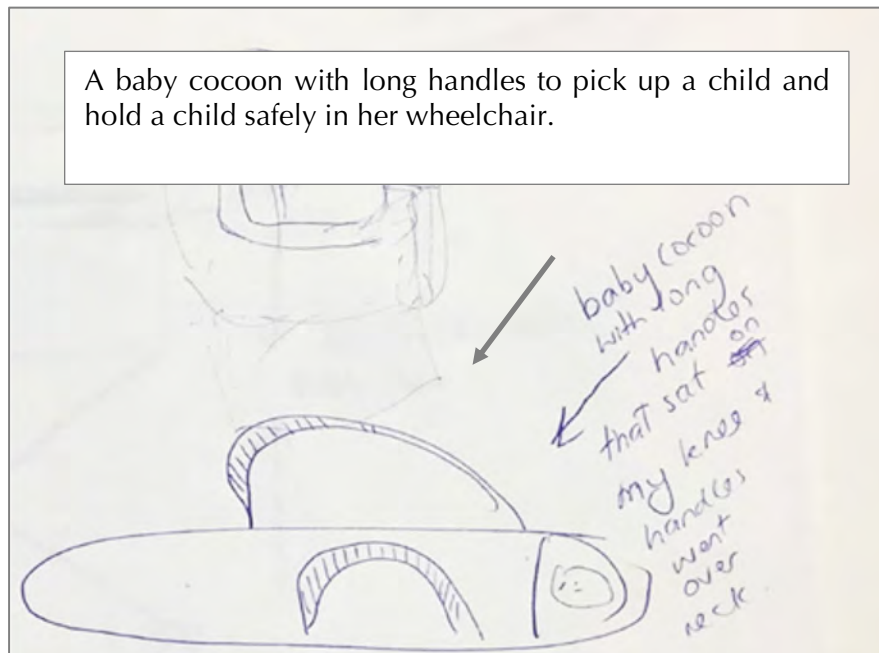
Figure 7.3. Allison's drawing, a baby cocoon to pick up a child from the ground.

From Allison's perspective, this idea would address important problems, including picking up a child and holding a child safely in a wheelchair. However, the concept of a baby cocoon may raise some technical issues, such as the handle not being accessible by a mother from a wheelchair, or a long handle may not be safe when put around a mother's neck (e.g. the weight of a baby in the cocoon while carrying in a wheelchair puts extra pressure on a mother's neck), or an infant may fall out of a baby cocoon while lifting. During ideation with the mothers, my emphasis was on the generation of ideas and hearing their dreams as opposed to considering the technical aspects and detail design. I applied this approach throughout our co-designing process, which helped me to encourage mothers to share their creative ideas.

Sophia made a simple object to help describe Allison's idea of a baby cocoon. It was like a blanket carrying a doll (Figure 7.4). Through a simple object, the mothers explained they needed a product such as a baby cocoon to pick up a child from the ground safely. The lack of accessibility to the floor was expressed through most of the ideas the mothers' put forward in the co-design sessions.

Figure 7.4. Object-making by Sophia, a baby cocoon to pick up a child from the ground.

Allison's other drawing was a multipurpose table which could be used as a cot, a bathing tub and a changing table (Figure 7.5). Similar to the previous idea, technical factors such as water temperature/circulation were not considered at this stage of idea generation.
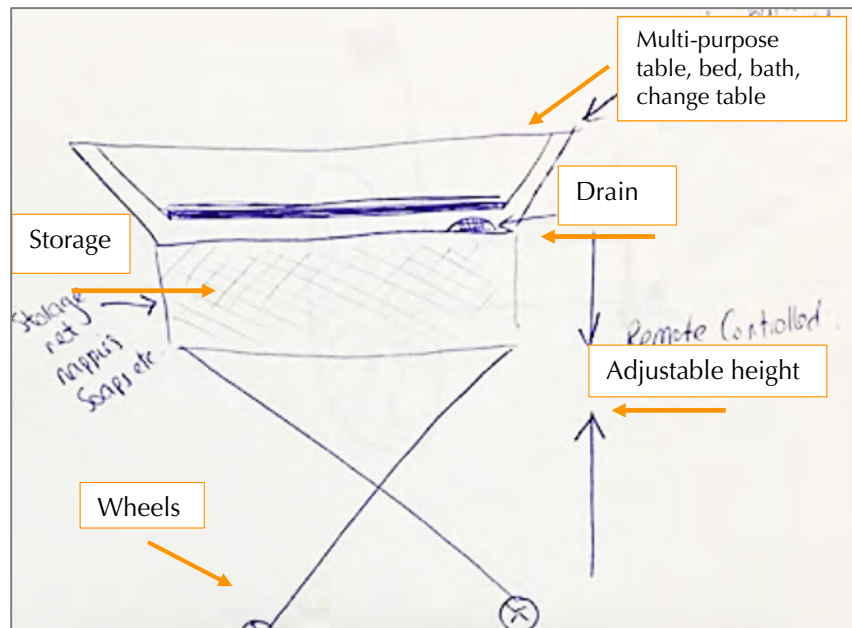
Figure 7.5. Allison's drawing showing a multipurpose table for bathing a child and changing nappies. Source: Author's photograph.

Allison explained a bucket and drain would attach to a changing table, which could then be used for bathing a child. Allison also drew wheels on the table legs to make it mobile and a storage net under the table for different items such as nappies, soap and shampoo. It was suggested the height of a table might be made adjustable by remote control.

Allison emphasised that safety played a key factor in using a product. All the mothers believed the lack of products which did not meet their physical needs would engender their fear to maintain their child's safety during some activities such as bathing their child. While Allison was drawing, she described her experience of bathing her child:

> "[I was]Bathing my son in the shower, in the bath I slipped and broke all my ribs on this side. I was trying to get him out […] and I slipped and he slipped. Fell out, cracked all my ribs on the side. It would be lovely to have (bathing a child), nice to have but I'd be too scared to do it on my own." (Allison)

Allison described the experience of falling in the shower and subsequently the fear caused by the incident led to her limiting herself from bathing a child again. The misfit of the relationship between the mother in a wheelchair and the bath environment had led to Allison feeling unable to bath her child safely and thus disabled her ability to do so as a consequence. According to Garland- Thomson (2011) "social justice and equal access should be achieved by changing the shape of the world, not changing the shape of our bodies" (p 597).

Allison's experience demonstrated that the lack of 'fit' products can result in mother and child injuries. Furthermore, it helped to shine a spotlight on how the lack of 'fit' products contributed to feelings such as fear and guilt, and as a consequence negatively impacted on the construction of meaningful mothering experiences. Moreover, through the temporal and spatial misfit which occurred between the mother and the material environment, the mother experienced a sense of not being capable of bathing her child.

Sophie drew a recliner with an adjustable backrest and height (Figure 7.6). This idea was inspired by the co-design toolkit which contained simple prototypes including a chair (section 4.2.4).

Sophia's idea was built upon by other mothers. When Sophia was drawing her idea, the other mothers made suggestions, and added more details and specifications. They proposed a remote control for a recliner and an option to make a backrest completely flat. The mothers mentioned they chose leather as a material for the recliner so it can be easily cleaned. They also stated that a firm material was the most appropriate material for their desired furniture. According to the mothers, firm furniture was more convenient for them to sit in and transfer from. As a result of spinal cord injury and lack of sensation and muscle control from their waist down, a chair with a firm material would help them to sit up straight while a soft material chair like a beanbag caused them to sink down into the chair. From the mothers' perspective, the idea of the recliner would

address important problems, including moving to the ground and spending time with their child on the floor. The majority of the mothers considered this idea as their favourite concept.
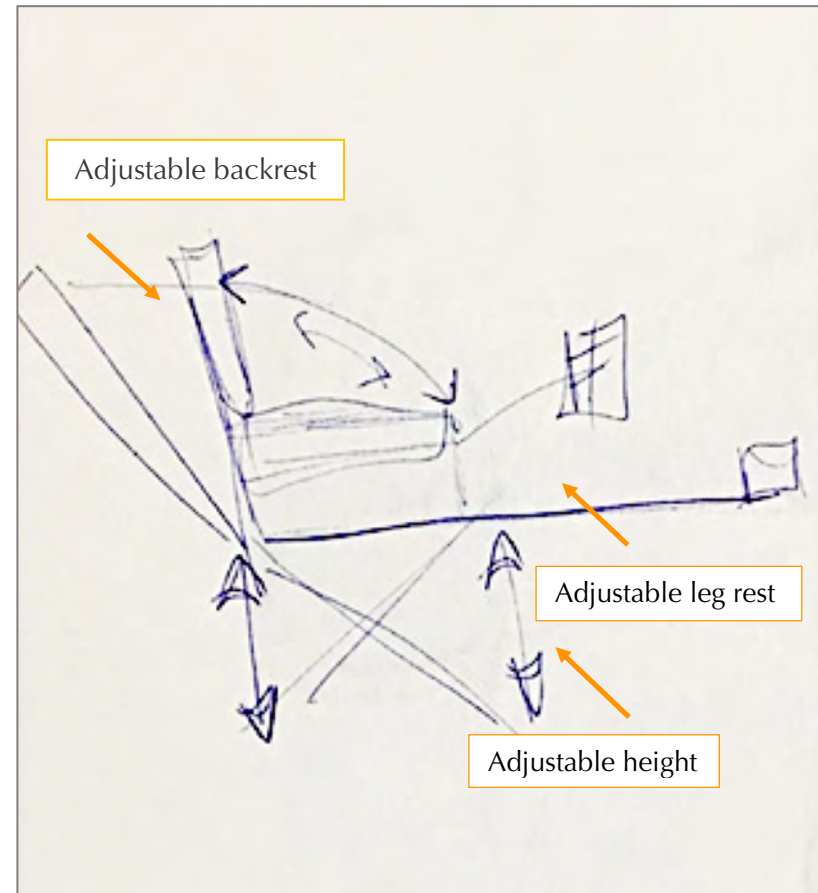
Figure 7.6. Lily's drawing showing a recliner with adjustable height, leg rest, and backrest.

Several mothers mentioned they preferred to spend some time out of their wheelchair. They considered that a 'fit' recliner would provide them with a convenient and adjustable place to sit out of their wheelchair. From their perspective, the recliner not only would create more opportunities to spend time with their child on the floor, but also provide them with more options of place to sit.

Given the mothers spent a significant amount of time sitting in their wheelchairs, having a 'fit' recliner would give them an additional choice of seating to sit in.

> *"I love getting out of my wheelchair, like after a long day in the wheelchair. I love to get out of it. I want to get out of it, different body positioning, different feel, I love your idea to get out of your wheelchair. More comfy." (Sophia)*

The majority of mothers considered using the recliner would provide them with an opportunity for more active engagement in their mothering tasks. For instance, the recliner would assist them to sit on the floor independently and provide them with an opportunity for more engagement in their child's developing skills:

> *"Babies spend so much time on the ground. So being able to easily get on to the ground (by a fit product) so that you can be down with your child doing tummy time or whatever, I love it". (Lily)*

The findings of Cycle III confirmed that the mothers' interest in using a product instead of relying on a third party not only arose from their desire to have more one-on-one engagement with their child, but also highlighted the impact of the social construction of a 'good mother' on the way the mothers perceived their mothering. For instance, Sophia considered how a 'fit' recliner would create positive feelings by providing her with more engagement opportunities with her child on the

floor; thus, facilitating mothering activities such as tummy time[13].

Similar to Lily, Sophia considered ensuring her baby spent time on the floor lying on its stomach as one of the mothering tasks which she preferred to do with her child. Sophia also mentioned using a 'fit' recliner had the potential to stop the negative feedback she received from health professionals regarding her child's development. Consequently, she would not feel she might cause any interruption to her child's developing skills.

> *"That's [a concept of a fit recliner] also going to stop a lot of the negative talk from the specialists like Plunket, etc. When Plunket came to the house they were like, 'your child's missing out on tummy*

time, it's irresponsible. They need to be on the floor'. So, to be able to get to the floor [by a fit recliner] we'll take away that perception that the kid's missing out and make the mothers feel the same." (Sophia)

The above excerpt highlights how the normative approach to mothering and the feedback the mother had received from a Plunket[14] nurse impacted how a mother constructed her mothering experience.

From Sophia's perspective, using a product would not only facilitate a mothering task, but would also help her to construct a positive perception about her mothering by following the dominant way of mothering, such as ensuring tummy time occurred for her baby. It seems the Plunket nurse's advice

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13 Tummy time refers to the time when an awake infant is placed on the prone position under the adult supervision. The main aim of the tummy time is to strengthen the infant's muscles and motor development (Wen et al, 2011).
14 Plunket nurses are registered nurses with a post-graduate qualification in community child and family health, and who work for the Royal New

Zealand Plunket Society (Inc) (Plunket). Plunket nurses provide families with health and wellbeing supports and consultation through Plunket clinics and home visiting. One of the main roles of a Plunket nurse is to support and educate families about the development skills of a child under five years old (plunket.org, 2020).

regarding her child's development was perceived by Sophie as a negative reflection on her mothering. As a result, she preferred to use a product to assist her to prove her capability in her child's development.

Using a product instead of relying on a third party was perceived by the mothers as an opportunity to shift from being a care receiver to be a caregiver. Several mothers considered that being a care-receiver would create negative emotions, such as frustration and humiliation. For instance:

> *"That really frustrated me If I'd have to get on the ground […] and then I'd just have to rely on somebody else and I found that humiliating." (Emma)*

From Emma's viewpoint, a mother is a person who cares for her child and does not need to rely on a third party to receive care for mothering tasks. Emma also described that the process of going down to the ground and then getting back into her wheelchair was time and energy-consuming. She also considered she needed a third party to help her to pick up her child when she was seated in her wheelchair. From Emma's way of thinking, asking for help in mothering tasks was a humiliating experience. Consequently, using a 'fit' product would change the role of the mother from being a care-receiver to be a caregiver. The shift from being a care-receiver to be a caregiver would help Emma to do mothering more activities in a similar way to the dominant way of mothering (i.e. able-bodied mothers).

The findings of Cycle III revealed that being a care receiver in mothering task was perceived as being passive recipients of care which was dependent on a third party rather than being an active caregiver. In summary, the findings of Cycle III acknowledged the social construction of an able-bodied mother was the dominant way the mothers construct their mothering world.

7.2 Home vs an institutionalised place

The focus of this research was to explore the interplay between mothers with SCI and child-caring products in the home environment. As such, one of the aims of Cycle III was to explore what home meant to the mothers.

'Home' was described as a space which reflected the way the mothers lived and interacted with other people like their family and friends. From the mothers' perspective, home embodied their lifestyle and their interaction with people who come to their home. They considered home to be a warm, welcoming and safe place.

> "Home for me is a warm, happy safe place. Where my daughter and my friends and everyone feels welcome and enjoys being." (Emma)

The above excerpt highlights the idea from the mothers' viewpoint, that home was not only a place where they physically live, but also an environment which connects to their feelings. Home provided them with a sense of security, belonging, and privacy. Moreover, the home environment furnished them with a place to interact with their family and friends.

Several of the other mothers also described home as a safe and convenient place. A safe place was described as not only a physical building made of wood and brick, but also a place of sanctuary where the mothers could engage with their child without any judgement. A home was a place where they were comfortable and be themselves.

> "A safe place is where I'm not stared at. It's where I am, whatever I need to do or say or be. I can just be myself there. I'm not on display to anyone else". (Hannah)

Hannah described a safe place as one where she could truly be who she was, and more importantly, this included being accepted as a capable mother. The above excerpt highlights how much other people's judgment and the feeling of being

monitored impacted the construction of her mothering experiences. It also illustrates how the mothers not only needed to fit themselves to the misfit products, but also people's judgmental eyes could force them to change how they 'mothered' to what was commonly perceived as a more acceptable way (i.e. the able-bodied mothers' way). Consequently, from the mothers' perspective, home was viewed as one place where they did not need to fit themselves to the misfit world.

Those mothers who stated their interest in using 'fit' products/furniture at home also emphasised their resistance towards using products or furniture with medical characteristics in their home environment. These mothers considered that a 'fit' product/furniture had to be in harmony with the rest of their home environment, specifically the design and decoration.

The majority of mothers considered products with medical characteristics made a 'home' seem like an 'institutionalised place'.

"Products could also exclude people because a house with people with higher needs can look a bit institutionalised if there are various products around. So, to a product to make it look normal and just part of the house not like the hospital setting. And that for me is very important. I don't like it to be out there things that you can see. So, if there is a product to have it be in harmony with the rest of the house." (Emma)

From Emma's perspective, a 'fit' product/furniture with medical characteristics in home gives a person a sense of being different and excluded from the majority of the people who are considered as being normal and able-bodied people.

The excerpts above can imply that there was a perceived difference between what the mothers considered to be a useful product and a desirable product. A useful product was described as one that addressed the mothers' physical needs, while a desirable product was considered more than this, one that met both the mothers' emotional, aesthetic and physical needs together.

According to the mothers, the desirability of a product was linked to their sense of inclusion and capability, rather than a sense of being different, excluded or ill. For the mothers it was important that home was a place with products/ furniture that met both their physical and emotional needs.

7.3 Designing a response to the research findings

This section includes the ideas and thought processes that were formed during my response as a design researcher to the research findings and included my explorations that built on the ideas and themes put forward by the mothers. These ideas are presented in two sections: Firstly, ideas that explored the notions of 'fit' child-caring products, and secondly, 'fit' chairs. The concepts and ideas presented below include the initial ideas and design experimentation, that primarily focused on child-caring products as a response to the findings from Cycles I and II.

As previously mentioned, I initially set out with a focus on child-caring products. Yet, as the research progressed (and informed by the data which emerged from those cycles), the scope of my design response broadened. In Cycle III, the research line of inquiry broadened to include any product or furniture in home environment that might enhance opportunities for the mothers with SCI to have one-on-one engagement with their children. According to the findings of the third cycle of research, products such as 'fit' chairs that met the mothers' needs would provide new opportunities for the mothers to engage with their child.

7.3.1 'Fit' child-caring products

This section presents samples of the ideas and concepts in response to the insights generated throughout the initial research cycles. It should be mentioned that all the ideas that are presented in this section are quick sketches and mock ups. The focus of these ideas was on finding creative design

solutions rather than exploring the technical details of the idea, or object being considered.

Ideas for bathing a child

As identified in Cycles I and II, bathing was considered as one of the most challenging activities for the mothers. Due to a child's body being wet and slippery, coupled with the mothers often having difficulty with their dexterity, the mothers reported being able to hold a child safely when bathing them was the main problem. These factors inspired me to explore concepts for a wearable baby carrier for use in bathing. A sample of some of the ideas explored with respect to the baby carrier for bathing is shown in figure 7.7.

Parents often used slings to carry a baby, but I thought that by making some material changes and customising a sling, a new baby carrier for bathing could provide a new product solution that would help make bathing their children safer and more enjoyable for those mothers living with SCI.

The adaptions I explored included adding adjustable Velcro straps and a waistbelt to support a mother's waist in order to distribute child's weight evenly while a mother who is in a wheelchair bathes her child. Given a wearable baby carrier might help a mother to bath her child without needing to hold her baby with both hands, a mother could face fewer challenges with holding the 'slippery' body of her child while bathing, and allow the mothers to be able to give their child more attention during bathing (e.g. playing and showing affection).

The material of the wearable baby carrier was anticipated to be similar to that commonly used for swimwear (polyester based). It was anticipated that the wearable baby carrier could be used for children between three to six months. While the wearable carrier could assist a mother to bath her child without needing to hold her child, these explorations revealed that further detail regarding the process of bathing, rinsing, and drying a child needed to be developed. At this stage of

ideation, I was initially focused on exploring opportunities to help a mother have better experiences while bathing her child from her wheelchair and maintaining physical proximity with her infant.

Front view

Back view

Adjustable shoulder straps

Adjustable waistbelt straps
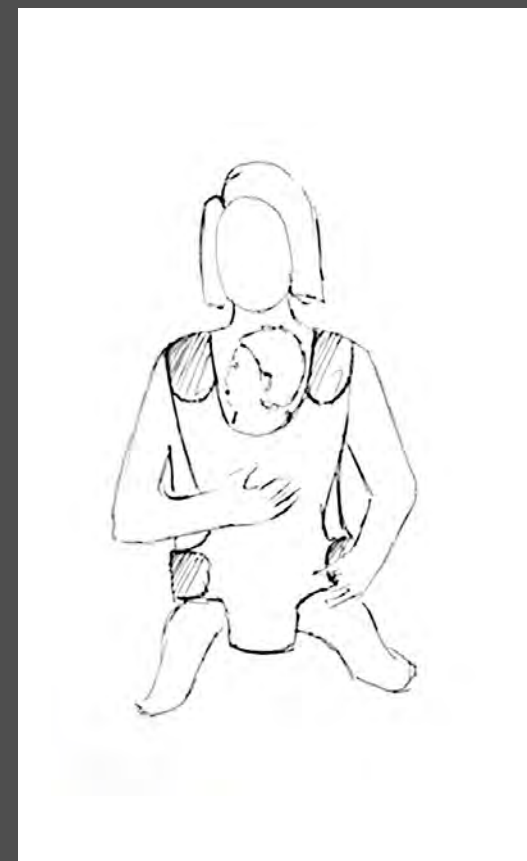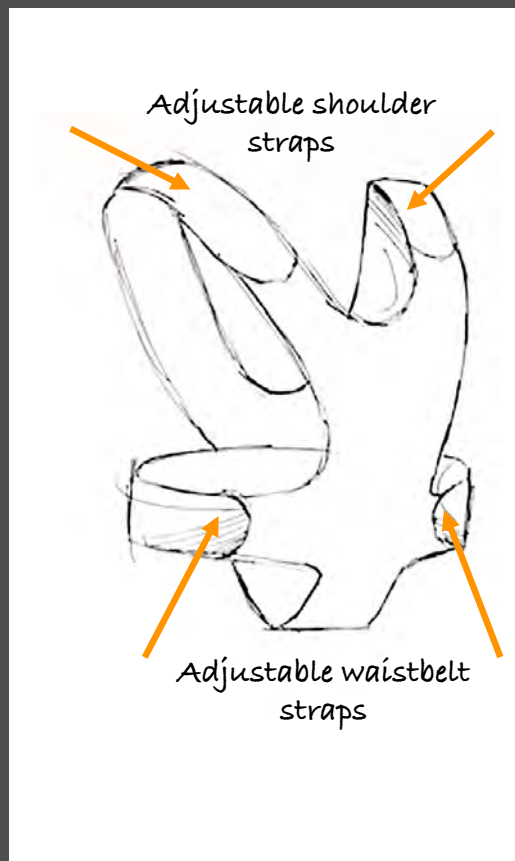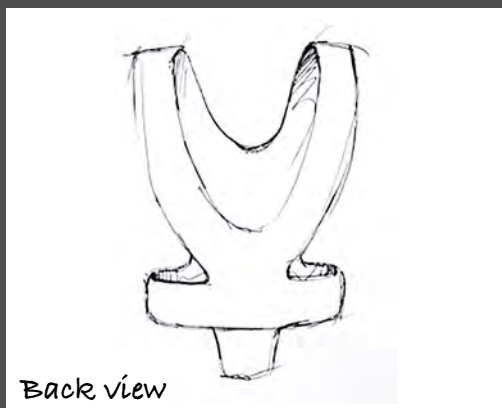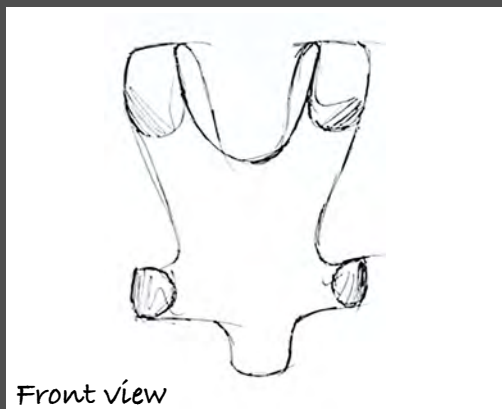
Figure 7.7. A sample of ideas to facilitate bathing a child for the mothers with SCI, Wearable baby carrier for bathing a baby.

I also designed some concepts to help facilitate bathing a child for the mothers from their wheelchair in a bathroom. In doing so, I reimagined the bath and explored other possibilities for bathing a child in the bathroom, without using a bath or a shower that already exists. In this Idea, a baby tub could be attached to a wall of a bathroom by wall brackets (Figure 7.8). This could provide mothers with more mobility and enough space for their wheelchair to ride underneath the baby tub. Thus, having easy access to a shower bath, water, soap, and shampoo would facilitate the process of bathing. This idea needs a large bathroom with enough room in order for it to be implemented.
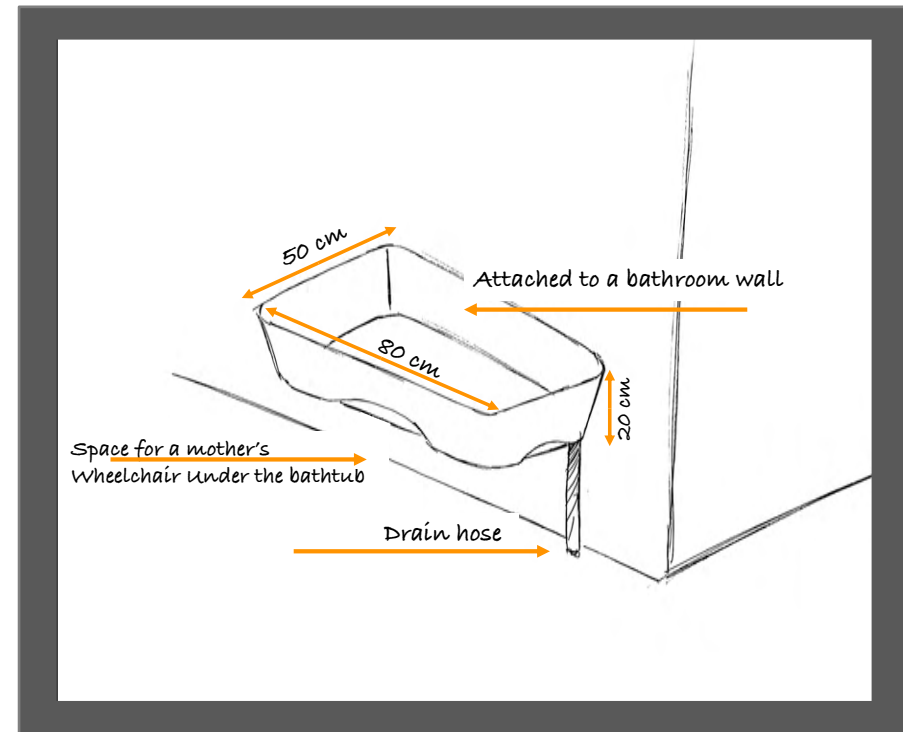
Figure 7.8. A sample of ideas to facilitate bathing a child for the mothers with SCI, A baby tub which attaches to a wall.

Bath plug

I designed some bath accessories such as a bath plug with a long handle to provide a mother with easy access to use a plug (Figure 7.9). I added a handle to the bath plug to facilitate its use for the mothers, in particular for those with dexterity difficulties.

Further Ideas for bath accessories were explored in Cycle III. From the mothers' viewpoint, small changes to those products that were used daily (such as a long handle for a bath plug) were described as a small but life-changing, when these were discussed with the mothers in the third cycle.
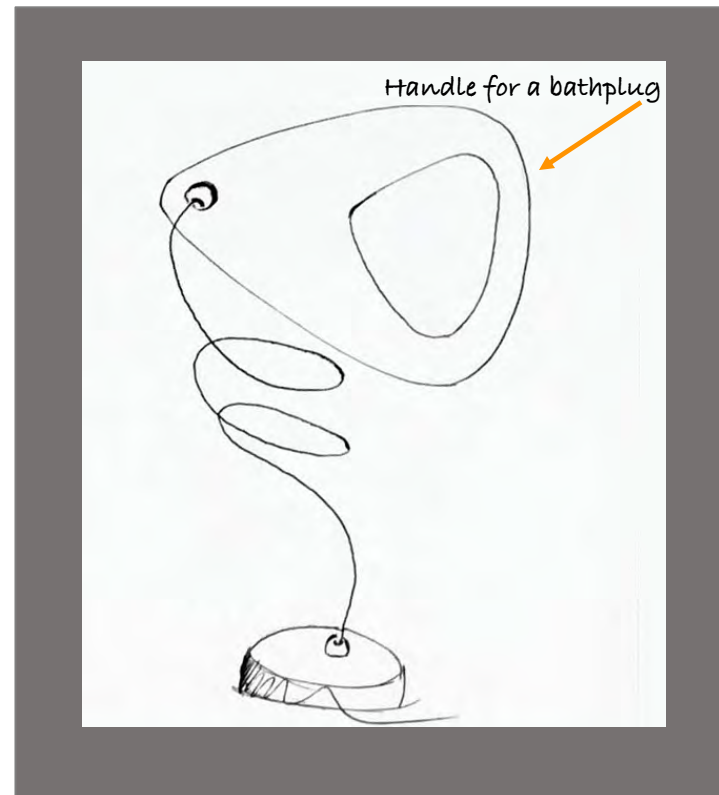
Figure 7.9. A sample of ideas to facilitate bathing a child for the mothers with SCI, A bath plug with a long handle.

Ideas for wheeling a wheelchair while carrying a child

According to the findings of Cycles I and II, holding their child while wheeling their chair was another challenge that was identified by the mothers. Keeping a child safe and maintaining the mother's balance while wheeling was a frequently mentioned as a major concern. The mothers described how people with SCI often lost their sensation of pain and pressure which would occur for the mothers by holding their child in a wheelchair. As the mothers do not have a sense of pain (as an alarm of extra weight) in their legs, prolonged weight can be a threat to their health. This is because, "loss of motor, sensory, and autonomic activity below the level of injury may result in a decrease in blood pressure. The parts of the body below the level of the cord lesion are paralysed, without sensation or diaphoresis." (Ray, 2005, p. 351). Furthermore, pressure ulcers are common consequences of spinal cord injury (SCI) (Garber & Rintala, 2003). Given that the mothers lost their sensation of pain and the extra pressure that might cause as a result of carrying their

child in their wheelchair, therefore, the idea of 'wheelchair seat' aimed to reduce the pressure of the prolonged weight of a child on the mothers' laps while carrying their child in their wheelchair.

I got inspiration from the idea of a car seat and designed a concept which could help a mother to hold a child safely and maintain the mother's balance and mobility. The idea of a 'wheelchair seat' aimed to eliminate the pressure from a child's weight on a mother's laps (Figures 7.10 and 7.11). The wheelchair seat would be attached to a mother's wheelchair via fasteners. Given that the mothers' wheelchairs may be different sizes, the length of the fasteners would need to be adjustable to fit different wheelchairs.

The concept of wheelchair seat was designed to carry a child aged six to twelve months. The seat would be attached with an adjustable height from a mother's laps without having any parts hanging over the wheelchair. This specific design aimed to reduce the risk of over front loading that could cause the

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wheelchair to tip over. However, there is a need to further investigate the detailed design of the mechanism and functionality of the 'wheelchair seat'.
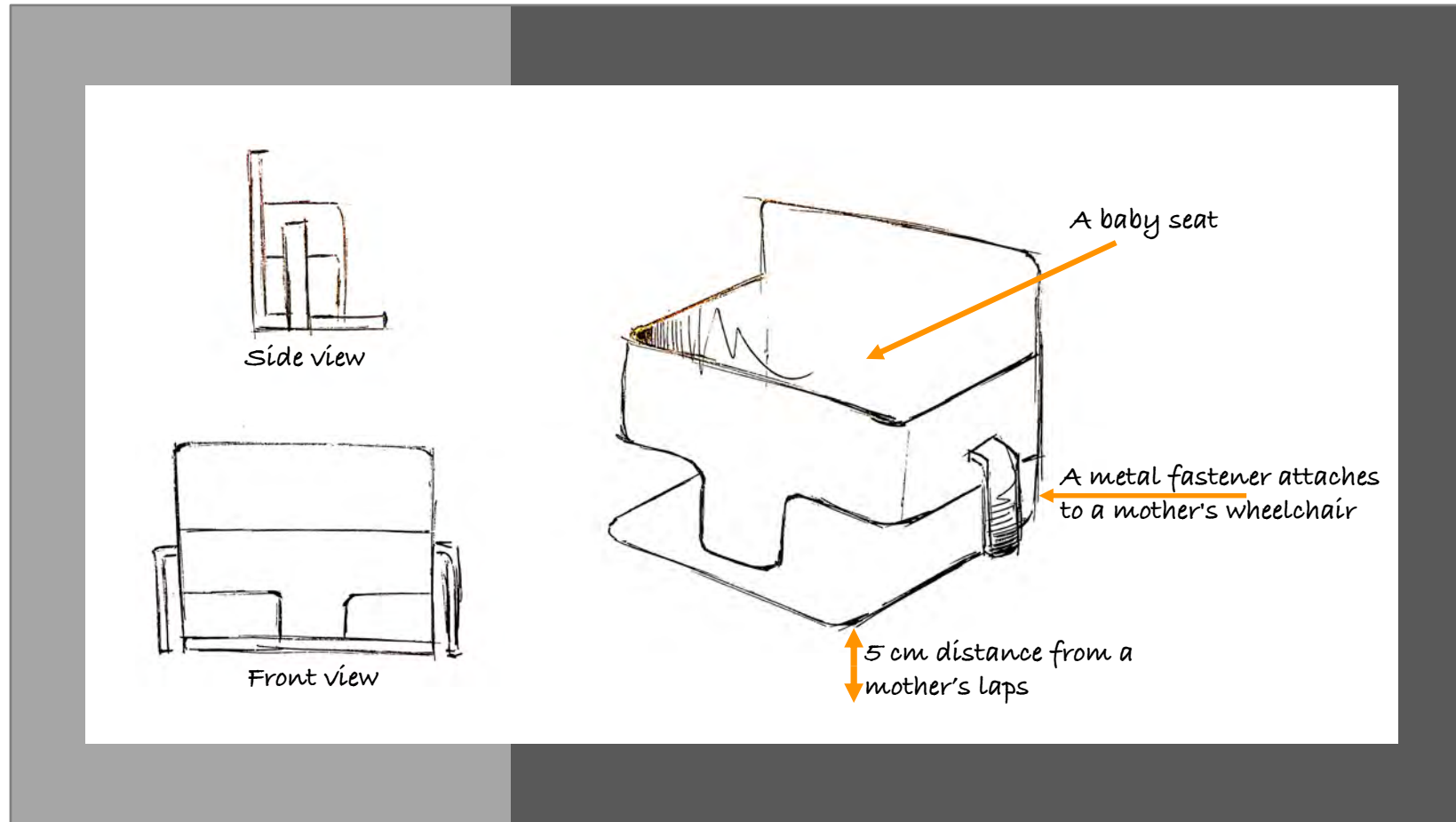
Figure 7.10. A sample of ideas to carry a child while wheeling a wheelchair, 'wheelchair seat'.
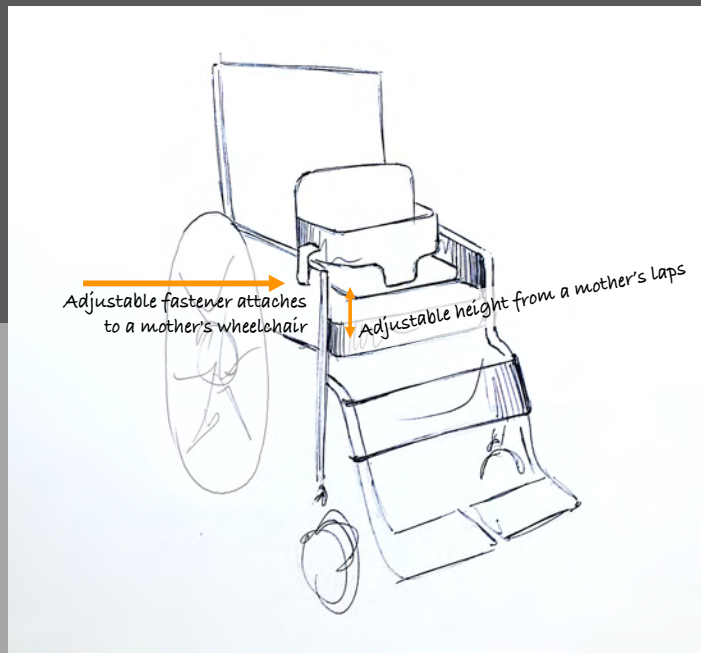
Figure 7.11. A sample of ideas to carry a child while wheeling a wheelchair, a 'wheelchair seat' attaches to a wheelchair.

Ideas for the mothers' wheelchair

As discussed in the co-design sessions with the mothers, adding new features to a mother's wheelchair might create new opportunities for them to have more one-on-one interactions with their child.

The mothers described that one of their common challenges was sitting on the floor or having the ability to go down to the ground from their wheelchair independently – without the assistance of others. This would provide them with greater mobility and improve the domain of their activity; for example, going down and picking up a child or other objects such as toys or puzzles. Consequently, I developed some ideas as new features for the mothers' wheelchair.   For instance, I explored the idea of a reclining wheelchair to provide a mother with an opportunity to go down the ground from her wheelchair (Figure. 7.12). In this idea, I adapted a ball screw mechanism[15] and servo motor[16] to lower the height of a wheelchair down to the ground. However, in order to be able to do this it is likely that the wheels of a wheelchair would need to be disassembled.

The idea of a new wheelchair (as above) for the mothers to facilitate mothering tasks was explored in Cycle III. The mothers responded to the idea of a new wheelchair as being a 'scary' concept. This is because, the mothers had stated they

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[15] "A ball screw consists of a threaded shaft and a nut, and either one can act as the traversing component. Ball screws work in a similar fashion to ball bearings, where hardened steel balls move along an inclined-hardened inner and outer race." (Kasberg, 2015)

[16] "The servo motor is a closed-loop mechanism that incorporates positional feedback in order to control the rotational or linear speed and position." (Gastreich, 2018)

would experience a significant amount of stress if they were to change their wheelchairs.
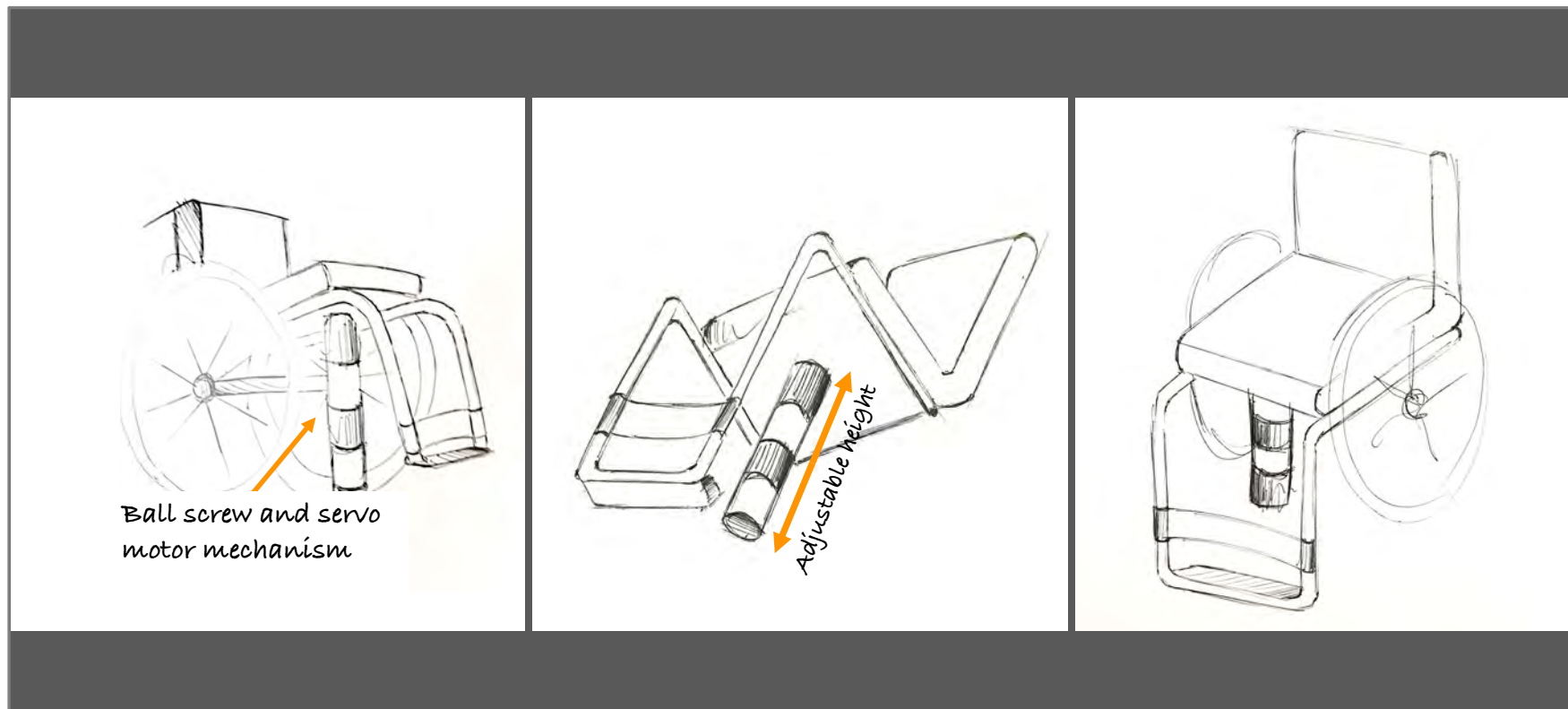
Figure 7.12. A wheelchair concept which enables a mother to access to the ground level.

7.3.2 'Fit' chairs

Co-designing with the mothers helped develop the designs, and sparked inspiration to explore the mothers' needs in regard to the visual appearance and function of a 'fit' product. I also found that the mothers preferred to use existing products, such as a modified recliner, instead of a new product, such as a new wheelchair. While I was personally more interested in designing a new wheelchair than modifying an existing chair, the findings of Cycle III confirmed that the mothers were not interested in the idea of a new wheelchair (see section 7.1).

The mothers described the idea of a new wheelchair as a 'scary' concept. This was because, from the mothers' perspective, using a new wheelchair while having a new child would present two big changes for them. Firstly, learning to use and become accustomed to a new wheelchair was thought to create extra stress for them to deal with at an already stressful time. Secondly, the mothers also expressed that they preferred to spend some time out of their wheelchairs. This challenged my idea that designing a new wheelchair would be appealing to them.

The research findings of Cycle II highlight that the mothers' first priority in mothering tasks was bonding (see section 6.1). From the mothers' perspective, having one-on-one interactions with their child played an important role in creating mother–child bonding. The mothers also described the floor as 'difficult space' to access. It led to limiting the mothers' opportunities to have one-on-one engagement with their child on the ground.

My analysis highlighted that, from the mothers' perspective, the idea of a 'fit' chair was a favourite concept that had the potential to make the inaccessible floor more accessible for the mothers. A 'fit' chair would also provide the mothers with an additional choice of seating and the opportunity to spend time out of their wheelchairs.

The mothers' interest in going down to the ground independently, without requiring assistance, shifted my attention from looking for new opportunities for the mothers through designing child-caring products, and helped to focus my attention on the idea of a 'fit' chair for their home environment. From the mothers' viewpoint, frequent and increased occasions of one-on-one engagement with their child on the floor played an important role in their mother-child bonding, and the 'fit' chair was viewed as an exciting opportunity to support this.

Insights gained through the co-design workshops assisted me to better understand how aesthetics contributed to the mothers' construction of meaningful experiences. According to the findings of Cycle III, the mothers wanted a 'fit' chair to be in 'harmony' with their home décor. They considered that using a product with a medical appearance would make their home feel more like an institutionalised place (see section 7.2). The mothers emphasised that they would prefer not to use a product unless it met their aesthetic expectations. Based on these findings, the idea of a 'fit' chair was further developed. These ideas were explored in Cycle IV.

Ideas for a 'fit' chair

Initial ideation of chairs involved a divergent process of developing concepts based on the mothers' ideas and dreams (Figures 7.13, 7.14, 7.15, 7.16). These ideas were then categorised into two key ideas, a 'fit' recliner and ottoman. These were developed using design characteristics and features that were identified during co-designing with the mothers in Cycle III.

I also made rapid prototypes of the initial ideas. I used a range of materials including cardboard and foam, as well as 3D printing to make these prototypes. All the prototypes were made in 1:10 scale. Some of these prototypes were later further developed and explored in Cycle IV.

According to the findings of Cycle III, from the mothers' perspective, the aesthetics of a product and harmony with the mothers' home decoration were identified as factors that they considered as being important. Through the idea of a 'fit' ottoman, I aimed to use a simple style which might more easily match with different styles of home decoration.

The concept of a 'fit' ottoman was aimed at enabling the mothers to move down the ground level. The ottoman could provide the mothers with an open space to interact with their child on the floor (Figures 7.13).

Sitting position

Ground level position

1

50 cm
50 cm

3

5 cm

2

Back rest

90 degrees rotation

90 degrees rotation

Leg rest
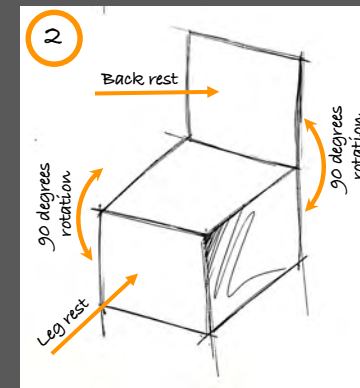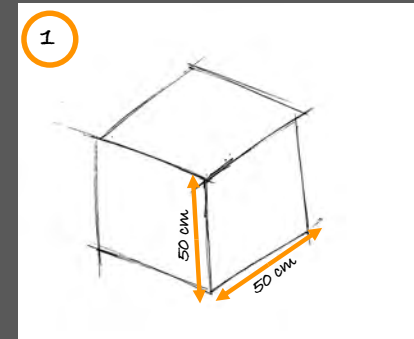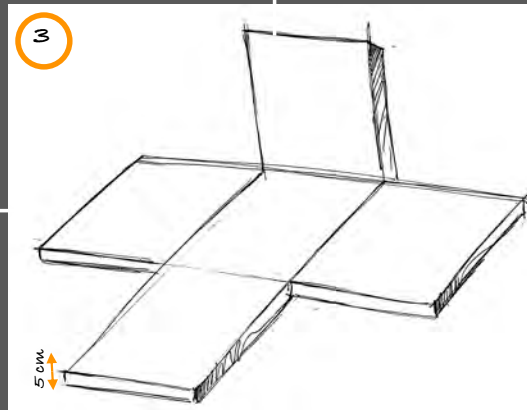
Figure 7.13. Ideas for a 'fit' ottoman.

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I proposed a scissor mechanism to be used to adjust the height of the ottoman (Figure 7.14).

Adjustable height

Mechanism

Scissor mechanism to adjust the height of the recliner
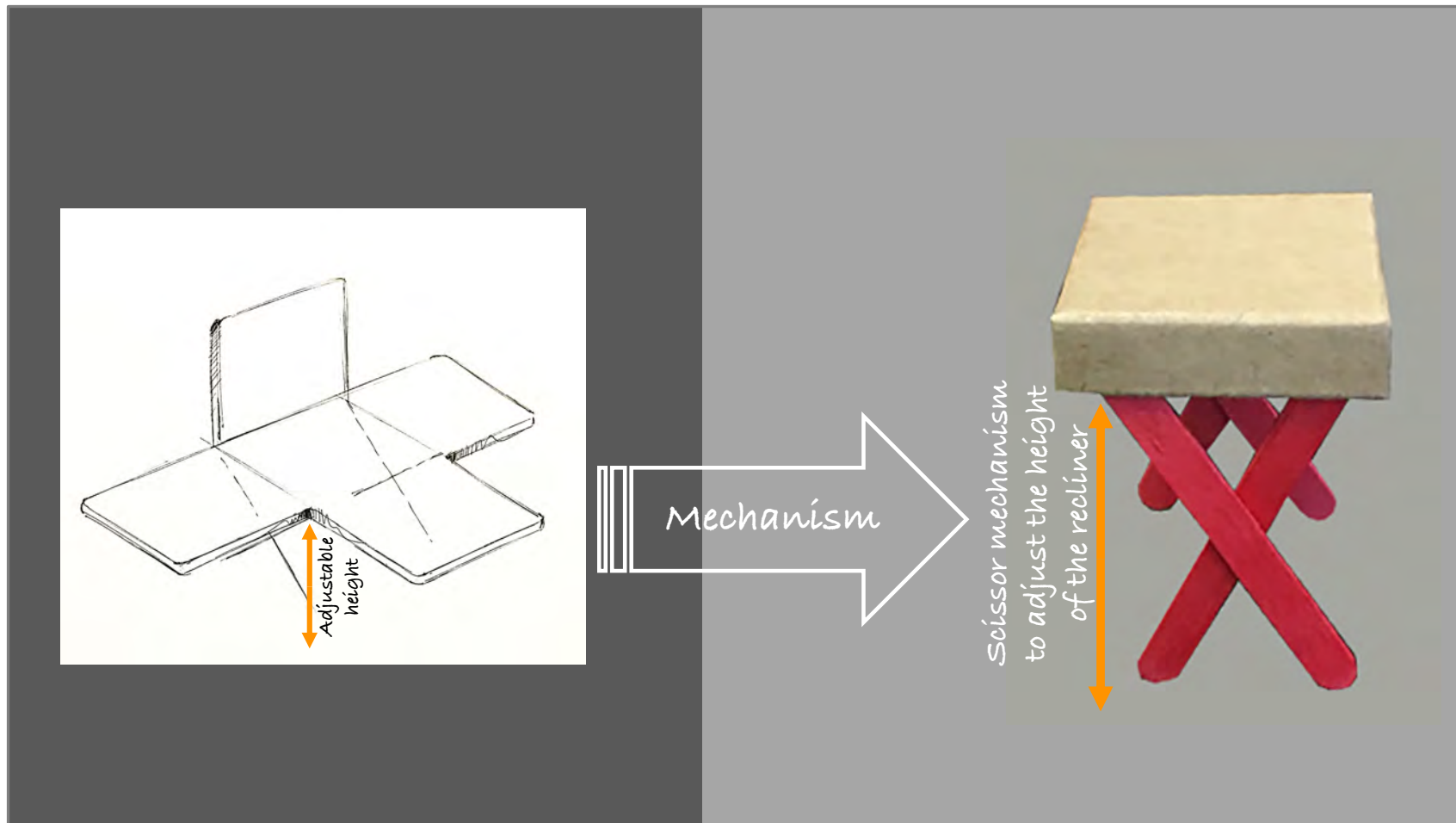
Figure 7.14. A proposed mechanism for the idea of a 'fit' ottoman.

Through the idea of a 'fit' armchair, I also intended to make the floor accessible for the mothers (Figure 7.15). I proposed a ballscrew mechanism with an electronic motor for the sofa legs to alter the height of the sofa.
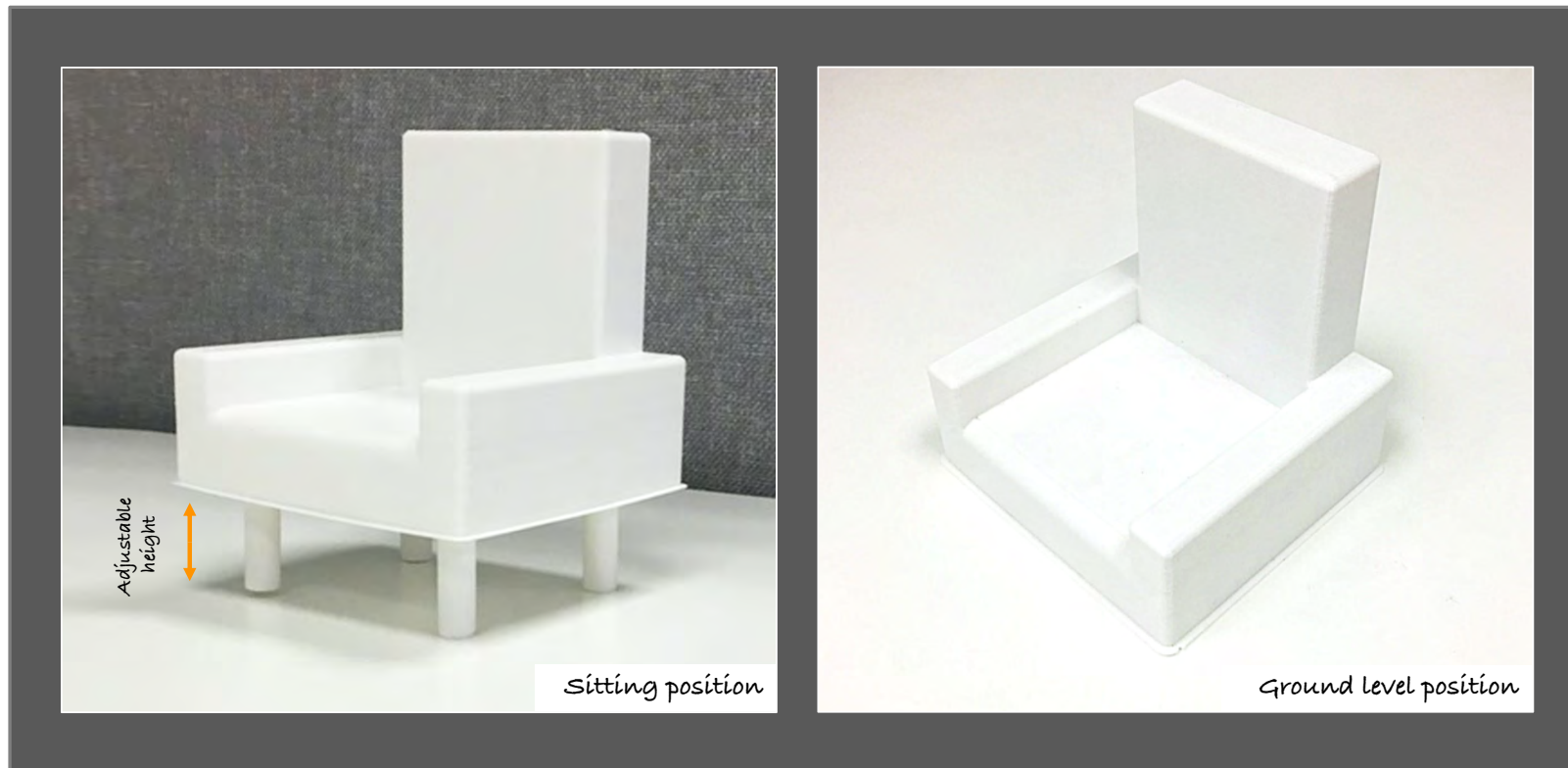
Figure 7.15. A sample of ideas for 'fit' armchair.

The concept of a recliner aimed to create an opportunity for a mother to spend one-on-one time on the floor. The idea would be that a 'fit' recliner had an adjustable backrest, leg rest and height (Figure 7.16). Similar to the idea of a 'fit' ottoman, I suggested that an internal scissor mechanism could be used to lower a mother down to the ground.
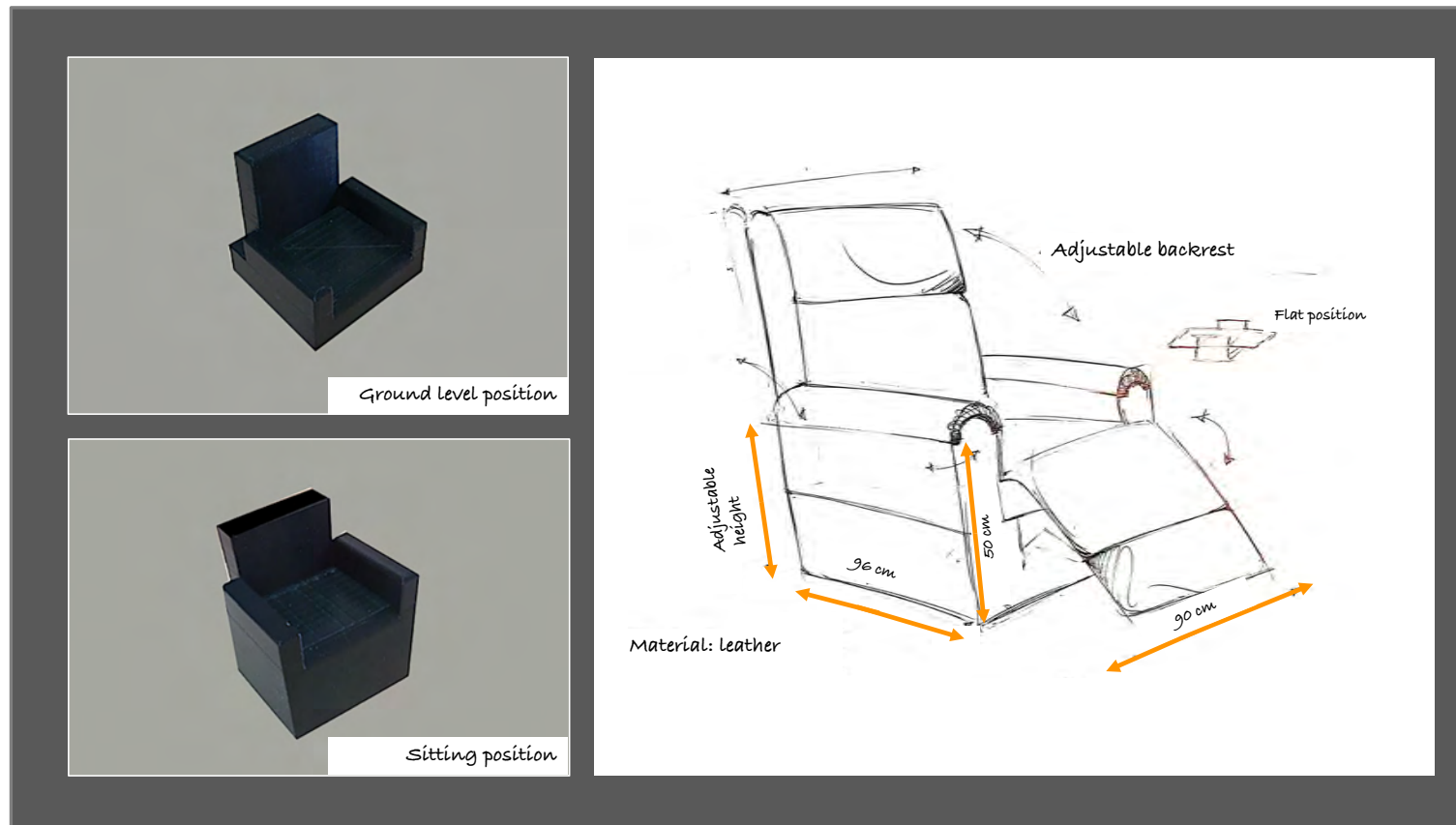
Figure 7.16. A sample of ideas for a 'fit' recliner.

Developing the idea of chairs

Through the immersive co-design process of Cycle III, I achieved a clearer understanding of the aesthetics, function as well as new insight into the desirability of a 'fit' chair for the mothers. Consequently, I continued to developed possibility of the chairs.

A 'Fit' recliner

According to the findings of Cycle III, the idea of a 'fit' recliner was one of the key concepts that the mothers were interested in exploring further and having me prototype on their behalf. Consequently, I made a full-sized cardboard prototype of a 'fit' recliner (Figure 7.17). The full-sized prototype helped me to gain a more complete picture at full-scale, and importantly in the context of a wheelchair. The seat height, depth, and width of the recliner prototype was informed by the average dimensions of a wheelchair (i.e. fully reclined height of the seat was 50cm, the minimum height of the seat off the floor was 10 cm, 50 cm depth and 50cm wide). The 10 cm off the floor (i.e. ground floor position) is the minimum height possible which is required for the proposed mechanism to fit underneath the recliner.
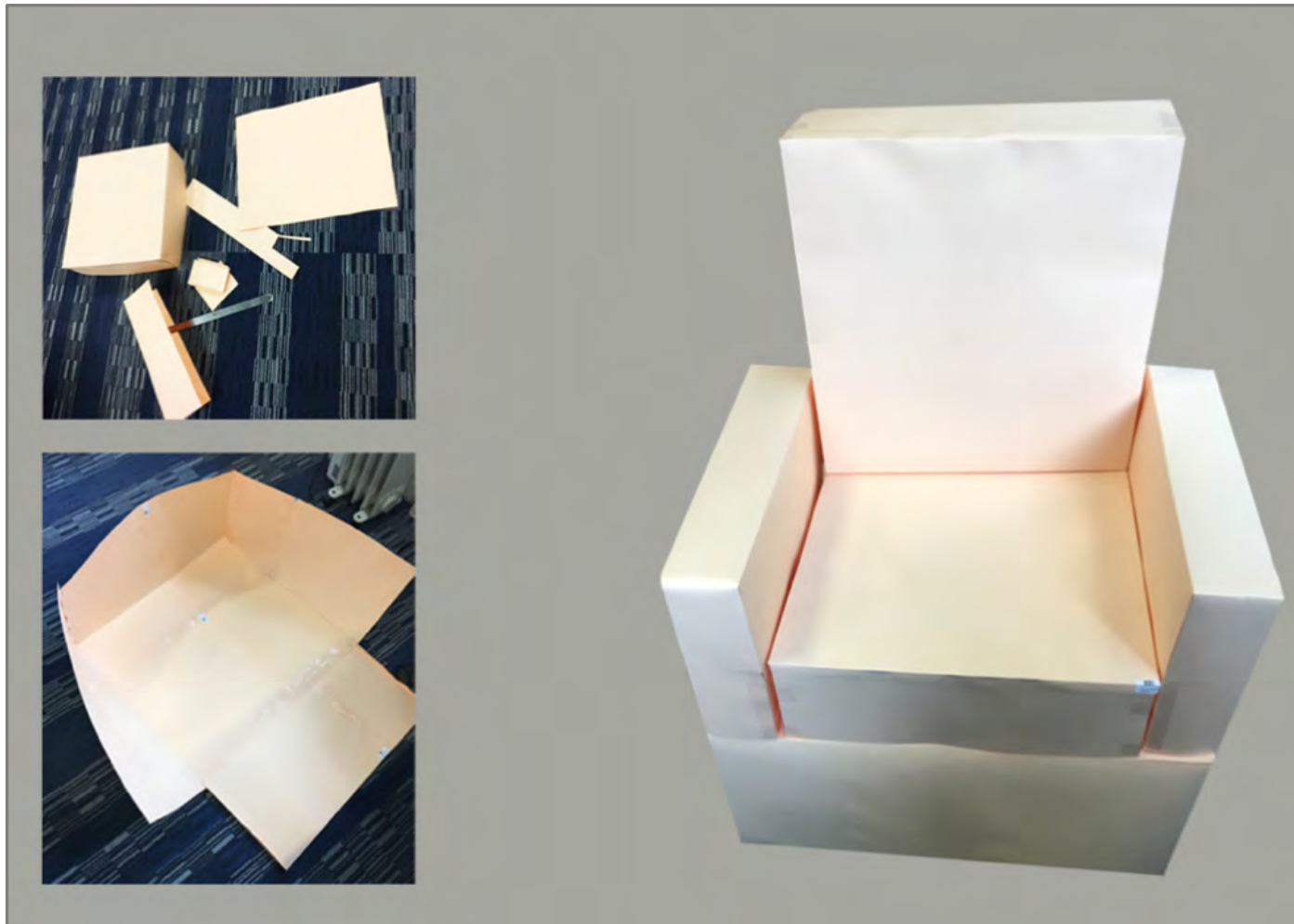
Figure 7.17. A full-sized prototype of the 'fit' recliner made of cardboard.

In addition, I made a 3D model and animation of the recliner (Figure 7.18). Please click on the link https://youtu.be/YfOdH-RQhoI to watch the animation of the 'fit' recliner showing that the backrest, armrest and height of the chair are adjustable.

The animated model assisted me to better understand how the recliner will work and was valuable and communicate to mothers. Based on the findings, the leg rest of the chair could lift and support the mother's legs. All the settings of the recliner including the backrest, armrest, leg rest and the height of the chair could be adjusted using a remote control.

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According to the findings of Cycle III, all the mothers described a recliner as one of their favourite choices. This was because, from the mothers' perspective, a recliner could meet their both physical and aesthetic needs.

Figure 7.18. The 'fit' recliner with the adjustable backrest, armrest, and height.

I also made the I:3 scale prototype of the recliner by CNC[17] using extruded polystyrene (blue Foam type). I used CNC prototyping to explore details curves (and cushions) more accurately (Figure 7.19).

Figure 7.19. The prototype of the 'fit' recliner in 1:3 scale.

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[17] Computer Numerical Control (CNC) "relies on digital instructions from a Computer Aided Manufacturing (CAM) or Computer Aided Design (CAD) file like Solidworks 3D. The CNC machine interprets the design as instructions for cutting prototype parts." (Roger, 2015)

A 'Fit' ottoman

The 'fit' ottoman was another idea for a seat for the mothers. I made the full-sized prototype of the ottoman (Figure 7.20). The minimal appearance of the ottoman aimed to address the mothers' aesthetic needs. This was because, some of the mothers considered that they preferred a simple and small chair in their lounge.

Figure 7.20. The full-sized prototype of the 'fit' ottoman presented in a mother's home environment.

The prototype was made of cushions, and the dimensions of the ottoman follow the average standard of a wheelchair seat and height. The seat's width and depth were 50cm. The maximum height of the seat was 50cm and the minimum height of the seat was 5cm from the floor. The full-sized prototype of the ottoman helped me to better understand how the ottoman would appear when fully lowered to the ground (Figure 7.21).

The backrest of the ottoman rotated 180 degrees and was able to be raised to support a mother's back. Then, two sides of the ottoman pop out and pivot out 90 degrees. As the chair went down, and the leg rest would raise what, to support the mother's legs.
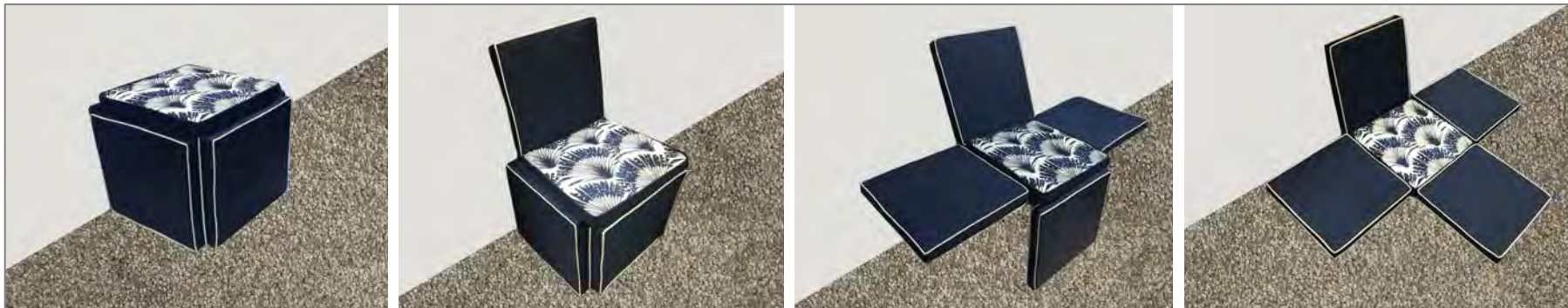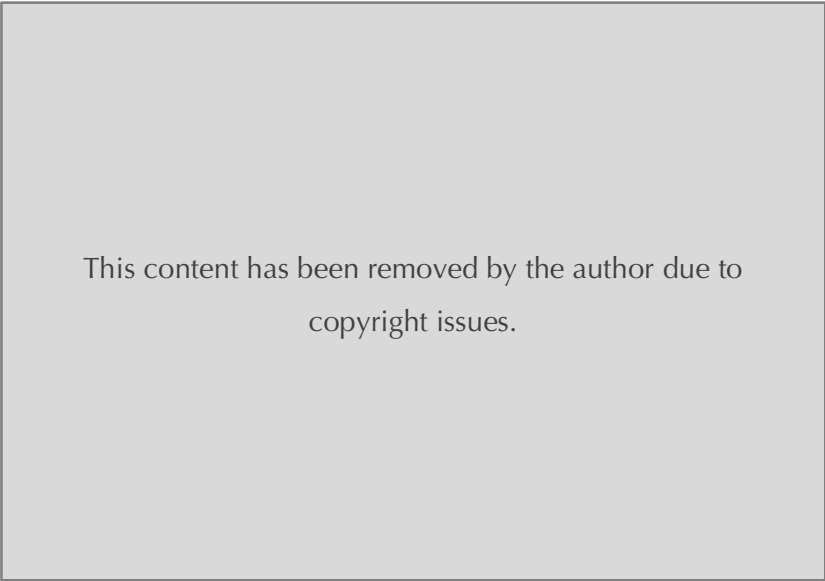
Figure 7.21. The image of a 'fit' ottoman showing that the backrest, leg-rest and height of the chair are adjustable.

I explored how the mechanism used in a bath lifter[18] could be applied in a similar way to the 'fit' recliner and ottoman (Figure 7.22). The mechanism is compatible with the structure of the chairs and would likely be able to lower the user completely down to the ground level. The mechanism has a frame with scissors and base plate to provide the required stability and safety support the users' weight. The overall weight of a bath recliner is approximately 12.5 kg, readily available in Aotearoa New Zealand, but expensive (average cost of a bath lifter is around $1300).

This mechanism enables the recliner / ottoman to be lowered to floor level. The remote control would allow adjustments when needed. The mechanism could potentially use a rechargeable battery.

This content has been removed by the author due to copyright issues.

Figure 7.22. The proposed mechanism for a 'fit' chair, Source: https://www.mobilitycentre.co.nz/shop/toilet-bathroom/bathroom/bath-boards-bath-seats/bath-lifter/?gclid=EAIaIQobChMI7_7nhoyO7gIVUilyCh29Ow06EAQYASABEgKBVvD_BwE

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[18] A bath lifter is chair that lowers and lifts a user in and out of a bath by reducing a user's physical strain and risk of falling.

In summary, this section presented my design response to the findings of research cycles through design processes and the ideas that were formed as a result of those findings.

7.4 Conclusion

Cycle III followed the findings of Cycle II. One of the most important findings from Cycle II was the mothers' interest in using a product instead of relying on a third-party in their mothering tasks. In doing so, in Cycle III, I focused on exploring the characteristics of products/furniture that met the mothers' aesthetic and physical needs. Firstly, I found that exploring the characteristics of furniture that meet the aesthetic and physical needs of mothers resulted in finding out what 'home' means to the mothers. More specifically, with regards to the characteristics of a 'fit' product/ furniture, the findings of Cycle III highlighted the aesthetic of a fit product/ furniture as being as important as its functionality.

The findings of Cycle III also re-confirmed the impact of the social construction of a 'good 'mother on the way the mothers perceive their mothering, previously identified during cycles I and II.

Secondly, the findings show that home was recognised as a warm, welcoming and safe place where the mothers were accepted as a capable mother. Therefore home was perceived as a space, or place, where they were able to care for their child without people's judgment. From the mothers' perspective, furniture and products that feature, or make visible medical characteristics that are more common in healthcare environments, make home feel more like an institutionalised place.

Following the data analysis of Cycle III, I found that the desirability of 'fit' products have the potential to help create a sense of inclusion and capability, instead of a sense of being different or ill from the perspectives of the mothers. This

significant finding was applied in the developing of ideas and prototypes.

The chapter finished by showing some of my responses as a designer to the findings of research cycles. Based on the mothers' ideas and dreams, two main ideas were formed; the need for a 'fit' recliner and an ottoman. The prototypes of the recliner and ottoman were further explored in Cycle IV.

Cycle IV: The mothers' feedback on prototypes

Introduction

Given that in this study, the mothers played an integral role in both contributing to, and informing the creative design solutions, in Cycle IV, I presented the two prototypes, which were shaped by the findings of the previous three cycles. The aim of the fourth cycle was to share the prototypes with the mothers and to hear their feedback, both about the 'fit' chairs and co-design process.

As I've shown in the previous chapters (5, 6 and 7) being unable to access the floor/ground area led to the mothers missing out on engaging in further meaningful experiences with their children when they were on the ground. As discussed in the previous chapter, the purpose of designing 'fit' chairs (Figures 8.1 and 8.2) was to create an opportunity for a mother with SCI to engage with her child on the ground level.

Figure 8.1. A visualisation of the 'fit' recliner, the recliner converts to a 'fit' chair and goes to the ground level.

Figure 8.2. A visualisation of the 'fit' ottoman, the ottoman converts to a 'fit' chair and goes down to the ground level.

The mothers described within each of the three cycles that their children mainly spent their whole time lying or playing on the ground, especially in the first three years of a child's life. Consequently, the mothers missed out on experiences such as spending one-on-one time with their child while playing on the floor, allowing them to have eye contact with their child while being at the same level. The majority of the mothers saw themselves as an observer- a mother who observes other people mothering their child.

Some of the mothers described how they even missed the opportunity to look eye to eye with their child because the mother was often looking down on her child on the ground from the height of her wheelchair. Consequently, the prototypes of 'fit' chairs aimed to construct more meaningful mothering experiences by creating new opportunities for the mothers to engage with their child, at the child's level. In doing so, the 'fit' chairs aimed to give the mothers to access the ground, the one space where their child occupied a lot of their

time and was previously inaccessible to a mother in her wheelchair.

The findings of the final research cycle are presented in two sections. Section 8.1 presents the mothers' feedback on the prototypes of 'fit' chairs. Then, section 8.2 discusses the mothers' feedback on being a participant in the co-design process.

8.1 From a heart-breaking mothering experience to a ground-breaking mothering experience

From all of the mothers' perspectives, the 'fit' recliner was viewed as a means to create new opportunities for them to engage with their child. The possibility of being able to more easily go down to the ground and spend time with their children, one on one, and playing at 'their level' was considered by the mothers' as a main advantage of using the 'fit' recliner:

> "I really think having that (recliner) would have made my experience with my children quite

different. I think it would have been able to give me a lot more opportunity." (Lily)

"I think so definitely being able to play with a little one, […] at their level. I think it's great. I'm really impressed." (Hannah)

Sophia considered the recliner as the biggest game changer, and considered it to be ground-breaking:

"Absolutely. This is the biggest game changer. That is possible, like one of the sole reasons that I had so much time support […], interrupt up the bonding time that I just wanted to have with my little one because it was a third party sitting there. […]Even now, my youngest is seven. And she loves me to go down on the floor and colour with her and play with the Barbies, maybe I would do that once a week or once a fortnight because it's so hard getting from the floor to back in my chair, I would have used this (the recliner) every single day and I would still be using it seven years later, because it's that important to me down on the floor playing. I think this is absolutely ground-breaking." (Sophia)

From Sophia's perspective, using the recliner would diminish her need to rely on a third party on many occasions. Consequently, it was perceived that the recliner would strengthen the bonding between a mother and her child by helping to support more quality occasions of engagement with her child. This excerpt highlights the meaningful experiences that the recliner could construct for a mother by allowing her to not only use it on various interactions with her child, but also enabling her to increase the frequency of those interactions. This increased ability to be able to access the ground more easily would facilitate activities such as colouring and playing frequently on a daily basis, instead of once a fortnight.

Sophia's use of the word 'ground-breaking' captures how the 'fit' recliner removed the barrier to the ground, and would allow her to interact with her child in her 'love language' (see section 6.2). As previously mentioned, love language, which refers to the ways mothers express their emotions to their child

through mothering activities, would be facilitated by 'fit' products/ furniture. This is because, the 'fit' products/ furniture such as the recliner could provide the mothers with new opportunities not only to physically connect to their child but also be able to connect emotionally.

All the mothers showed strong interest in the prototype of the recliner. However, the prototype of the 'fit' ottoman was not preferred by the mothers. The mothers stated that they would not feel confident or safe enough to consider using the ottoman. The majority of the mothers considered that the ottoman could potentially create the risk of their falling from it. This was because the ottoman did not provide enough physical structure for the mothers to support their bodies:

> "So, for me, it's very clear that the recliner would work better than the ottoman. And that is because the recliner gives me more ability to sit in because I can't hold myself up. It (ottoman) wouldn't give me enough structure, to be able to set out by myself". (Hannah)

Given that a SCI is a damage to the spinal cord that results in the loss of feeling and control of movements and muscles of the lower body, all the mothers felt the armrests of the recliner would assist them to maintain their balance, but the ottoman was not a safe chair for them to sit on and hold their bodies because of the lack of armrests and back structure to support them.

With regard to the recliner, all the mothers considered it to be a comfortable, reliable, and safe chair that they would be delighted to use. The low risk of dropping a child and being able to transfer from their wheelchair to the recliner easily by raising up the armrest was voiced by the majority of the participants.

From the mothers' perspective the 'fit' recliner not only provided new opportunities for the mother to engage with her child on the ground, but it could also be used for different purposes such as breastfeeding , snuggling, and doing yoga:

"I think that this would be amazing for feeding the baby, for getting down on the ground, Tummy time. I feel like that will give you that safety element of being able to feel really comfortable and get down onto the ground. You don't have to worry about strength. I think it would be really amazing, you'd have the snuggling element on the chair, the breastfeeding, the support and ability to even breastfeed more comfortably in." (Lily)

"Even I like to do yoga. You go down on the floor (by the 'fit' recliner)." (Sophia)

The interviews highlighted that although the 'fit' ottoman had a smaller leg rest and therefore provided more open space in the lounge area than the recliner did, all the mothers preferred the 'fit' recliner as the most useful product solution. This was because, firstly, the recliner was seen to create enough space for mothers to have one-on-one interaction with their children. For example, when asked why she preferred the recliner chair to the ottoman, Hannah replied:

"So, for me, I think this (ottoman) is a great idea because it does create much more space for baby to come on both sides […] but I think it's (recliner)

enough. I think it's (recliner) close enough, it's not on the ground, but it's close enough to the ground, and it's much. It's much different than, say, being in this wheelchair." (Hannah)

Secondly, all the mothers considered that the recliner's padding and armrests were important elements to maintain their balance, stability, safety and help to prevent falls:

"I would just fall over off the side [of the ottoman. It's (armrest) part of the safety for me. very clear to me that I could use the recliner." (Hannah)

"I just don't think it's (the ottoman) comfy […] You could spend a lot more time in here (pointing to the recliner). It's still a struggle when you have the toddler pushing you over, this [referring to the ottoman] doesn't have any bilateral support and for the balance and stability". (Sophia)

All the participants stated that the padding of the 'fit' recliner would make it more comfortable. Thus, the extra padding of the recliner would also allow the mothers to sit for much longer periods:

"The advantage (of the recliner) is that there's enough padding, that I wouldn't have to worry about pressure. So, I could sit in the recliner for much longer period of time. The Ottoman doesn't have enough padding for me to sit for a long period of time, and the footrest would also protect my legs. So, there'll be enough padding the arm rest would hold me in a more upright position without the arm rest." (Hannah)

"(Regarding the ottoman), I'd be so sort of worried about not being comfortable, or I might fall over rather than being able to focus on my child which, if I used this one (the recliner) which not only looks 100% better. But it looks safe and appropriate for a spinal injury then I could feel comfortable in my situation to really focus on my baby. So that will hundred percent for me." (Emma)

"The muscle atrophy that often results from SCI, combined with the loss of other soft tissues, reduces the area of the surface and the distribution of pressure to the underlying structures. Pressure, defined as force per unit area, increases rapidly with decreasing contact area. High pressures on the seating surface lead to pressure sores, a major concern of persons with SCI for both health and quality-of-life reason." (Gutierrez et al., 2004, p. 374). Consequently, people with SCI are advised to look after themselves to prevent medical complications associated with their condition. Both Hannah and Emma referred to the recliner as a product that could provide them with features that minimise the possibility of developing pressure sores.

Being 'chunky' and big were mentioned as key reasons as to why the recliner was preferred. These physical features were considered to construct the sense of safety and convenience for the mothers:

> *"It's (recliner) chunkier and safer would definitely be my pick. At this time of nurturing and childbirth and breastfeeding and bonding, I think I like bigger and safer and cosy."* (Sophia)

As previously discussed, spinal cord injury causes the loss of the movement and sensation in both legs, and consequently, all the mothers stated that a footrest would be necessary to

protect their legs. All the mothers mentioned that the feature of having padding and being 'chunky' appealed to them because spinal cord injury affects the ability to move, feel and balance (the amount of movement and feeling depends on which level of the spine is injured). From the mothers' perspectives, the padding and armrests of the recliner would assist the mothers to maintain their balance and hold their body while sitting in the recliner. But according to the mothers' feedback, the ottoman did not fit their body to support their balance.

8.2 The tangible outcome made the co-design process more meaningful

I applied the collaborative design process so that the mothers played a key role throughout the research, which helped to ensure their inclusion in the knowledge development. This was achieved by their sharing of their mothering experiences, idea generations, and concept developments. In the final research cycle, I also explored the mothers' perceptions of their participation in our co-design process. I aimed to explore the role of the co-design process in facilitating mothers to express their ideas and share their mothering experiences. I asked the mothers about their experience in the co-design sessions. The mothers mostly found co-design to be a useful way to share their experiences and ideas. They considered the co-design sessions as an easy and enjoyable process:

> *"Amazing. Easy to share. Really enjoyable process." (Sophia)*

From the mothers' viewpoints, the two prototypes were identified as the tangible outcomes of the co-design sessions that were conducted in the previous cycles (Cycles II and III).

> *"It's been great. I really, I really liked the way you just took all that information and were able to create a product that I can see. I can say absolutely how that would work. […] That that's really impressive to me." (Hannah)*

Similar to Hannah, all the mothers were impressed when they found that our co-designing led to the transmission of their abstract desire to a tangible prototype. The main aim of applying co-design was to give voice to the mothers to not only be design recipients but also to influence the design and decision-making process. Consequently, co-designing with the mothers through generative tools provided us (the mothers and me) with a clear understanding of the mothers' aesthetic, emotional and physical wants.

In other words, the application of generative tools assisted us to translate the mothers' unmet needs into meaningful experiences. For instance, one mother stated that although the process was interesting, what could be achieved through the activities in co-design sessions had initially been unclear to her. However, she specifically indicated that the presentation of the prototypes (i.e. tangible concepts) helped her better understand the activities that had taken place through our co-design process.

> *"(During co-design sessions) I didn't see what we were trying to achieve. now I get it, I get it."* (Emma)

Then she continued:

> *"I feel quite emotional. I feel quite emotional (there is silence, she tears up and smiles). Oh, my hair stands on my arms. I think that is just fabulous."* (Emma)

Emma was emotional because she could now clearly see a product that could fit her needs would have created for her more opportunities for one-on-one engagement with her child. Consequently, she would not need to 'fit' herself to a misfit product to communicate her love to her child. She was also moved to know that the product was the direct result of her contributions through sharing her mothering experiences and ideas.

I finish this chapter with Emma's excerpt because this was very similar to the feeling I had when I was reading the mothers' transcripts in Cycle IV.

8.3 Conclusion

In Cycle IV, I explored the mothers' feedback on the prototypes of 'fit' chairs. The subjective aspect of the co-design sessions was important to give voice to the mothers to become immersed in their experiences. The design aspects of our co-design sessions helped us to explore new opportunities for the mothers to construct meaningful mothering experiences.

The findings of Cycle IV showed that the mothers were interested in the prototype of the 'fit' recliner. This was because, the recliner could provide new opportunities and occasions for the mothers to have one-on-one engagement with their child on the floor. All the mothers showed their interest in the appearance and desirability of the 'fit' recliner.

The mothers enjoyed the process of co-design in Cycles II and III, and described how the co-design sessions enabled them to share their experiences and ideas. I also found that a physical prototype (i.e. the prototypes of the recliner and ottoman) as a shared language would provide the mothers with a better understanding of the whole process of co-designing.

Chapter 09. Discussion

Introduction

In this chapter, I discuss the findings of the research cycles by linking my integration of feminist disability theory and co-design as the main theoretical arguments in the methodology chapter. The study was guided by two key research questions:

- How do mothers with SCI construct meaningful mothering experiences?
- How can child-caring products improve meaningful mothering experiences for mothers with SCI in the home environment?

This final chapter aims to bring together the research findings that have been explored within the four distinct but related cycles. I discuss in more depth and more cohesively how the themes constructed during the thesis represent a contribution to knowledge in the discipline, and relate these to the wider literature. In particular, I discuss three main points in the following sections. First, section 9.1 describes how the integration of feminist disability theory and co-design provides new understanding about the construction of meaningful experiences for the mothers living with SCI. Second, section 9.2 discusses the role of products to improve meaningful mothering experiences with SCI. Third, contributions of the research are considered along with the limitations of the study in section 9.3. Finally, the directions for future research are suggested, in section 9.4, following the summary of key findings and research contributions.

9.1 How do mothers living with SCI construct meaningful mothering experiences?

The integration of feminist disability theory and co-design provided me with a lens to explore the construction of meaningful experiences for mothers living with SCI by focusing on the mothers' voices and experiences (section 9.1.1). Another outcome of focusing on the mothers' voices as a unit of analysis was to highlight the effect of societal attitudes on the construction of meaningful mothering experiences with

SCI (section 9.1.2). The discussion of the findings of the construction of meaningful mothering experiences is presented below.

9.1.1 The mothers' perspectives on meaningful mothering experiences

Applying a feminist disability lens throughout this research assisted me to be concerned about the representation of mothers with SCI in the research. This was because feminist researchers epistemologically and methodologically investigate the issues of difference, voice and silence in women's lives (Hesse-Biber, 2007). Consequently, the intersection of sexism and disablism provided me with an approach to be able to gain insights into the understanding of mothering experiences with SCI.

Feminist disability theory enabled me to analyse disability as embodied identities that are constructed in social contexts (Garland-Thomson, 2002). The critical approach of feminist disability theory to disability as a system that stigmatises human variation provided me with an insight into the way the mothers living with SCI are discriminated against by not having equal access to products that suit their bodies.

By integrating feminist disability theory and co-design I was able to reconsider the position of mothers with SCI. Feminist disability theory criticises the 'normate' approach to women and the way human differences are perceived in society (Garland-Thomson, 2009; Thomson, 1996, 1997). As described in Chapter 3, the term 'normate' refers to privileged bodies that are considered as normal and perfect bodies in society (Garland-Thomson, 1996, p. 8). This theoretical underpinning offered me an alternative lens to explore the way the mothers in this study construct meaningful experiences through using child-caring products by considering the mothers' physical differences and highlighting how their needs are often neglected by the design discipline.

The integration of feminist disability theory and co-design provided me insight into how the social construction of able bodies and the normative approach in mass production and manufacture results in privileging able-bodied mothers in product design. According to my findings, (described in Chapter 5) all the mothers in my study reported the lack of availability of 'fit' child-caring products.

The integrated feminist disability theory and co-design provided me with a better understanding of what constituted meaningful mothering experiences and how these could be created through co-design's use of a variety of tools and processes to generate my data. Hence, the one-on-one interviews combined with the co-design process gave me the opportunity hear the mothers' challenges and experiences in more depth.

According to Garland-Thomson (2005), feminist disability studies aim to break stereotypes regarding disabled women. As explained in Chapter 3, feminist disability scholars look at disability in a new way and seek new possibilities from the social model of disability. Garland-Thomson (2005) considers that feminist disability theory challenges a hegemonic perspective, which looks at disability as an inherent inferiority. In contrast, feminist disability studies emphasise the influence of the interplay of bodies and environments in shaping meaning. Through the research cycles, by giving voice to the mothers, I explored these mothers' challenges and meaningful experiences in relation to mothering with SCI.

The findings of the first cycle shed light on the difference between the mothers' challenging experiences and their meaningful mothering experiences. From the mothers' perspective, maternal bonding and intimacy that were created through mothering activities resulted in meaningful experiences. Developmental psychology research also shows that the mother-child relationship is very important to a child. According to the Attachment Theory of Bowlby (1951), physical proximity has a significant impact on the mother-

child relationship. Further studies acknowledge that mother-child attachment improves child development (Holmes, 2014; Sullivan et al., 2011).

The mother-child relationship is a process that forms during pregnancy. Sroufe (2005) claims that the experience of infant attachment will never be lost by the infant. Sroufe's study (2005) sheds lights on the important impact of mothering attachment on a child's functional, emotional and social development. The mother-child attachment is initiated during pregnancy when a foetus is able to recognise the mother's voice and odour (Sullivan et al., 2011). This mutual attachment continues after childbirth. The infant's auditory and olfactory senses allow them to know their mother (Varendi & Porter, 2001) and be calmed by her presence (Rattaz et al., 2005). According to Giustardi et al. (2011), bonding needs time to develop and is not limited to just the short time after birth. The bonding process is a gradual development of the mother-child relationship. In the first three years of a child's life, bonding develops within a caring and consistent relationship between a mother and her child.

In all the research cycles in this study, the majority of the mothers reported that they had limited occasions for consistent one-on-one engagement with their child. The majority of the mothers also described that they had missed many opportunities to interact with their child without the presence of a third party. Some mothers reported that the limited opportunities to interact one-on-one with their child led them to feel other people were mothering their child. My findings highlighted that those mothers in my study with a higher level of SCI had less time and fewer occasions than those mothers with a lower level of SCI to engage with their child without the presence of a third party.

My findings highlight that, from the mothers' perspectives, mothering tasks are not only a physical activity but also a love language used to express their love to their child. According to Chapman and Campbell (2016), parents show their love to

their child through five love languages: "physical touch," "words of affirmation," "quality time," "gifts" and "acts of service" (p.8). Chapman and Campbell (2016) describe physical touches including kissing, cuddling and physical proximity as ways that parents show their love to their child, especially in the first years of the child's life. 'Words of affirmation' refers to using positive words to encourage and praise a child. 'Quality time' refers to the use of one-on-one time to pay undivided attention to the child. Giving gifts (such as a small present in a child's lunch box or a note to express love to a child) is the fourth love language. Acts of service, as the fifth love language, include addressing the child's physical and emotional needs such as taking care of the child during illness.

According to my findings, the mothers suffered from limited opportunities to express their love to their child through quality time and acts of service. Consequently, as described in Chapter 6, mothers preferred to use a product instead of relying on a third party when engaging with their child. From the perspective of the mothers', having to rely on a third party could interrupt their mother-child bonding. This was because the permanent presence of a third party may impact on the mother's quality time with their child by limiting the mother's opportunity to spend one-on-one time and build up intimacy with their child.

Furthermore, having to rely on a third party provided the mothers with limited occasions to perform acts of service as a way to express their love to their child. As shown in Chapter 6, the presence of a third party can make a mother feel like an observer. According to the findings, feelings such as those of being an observer have a negative impact on the construction of a meaningful mothering experience. For example, several mothers stated that they wanted to be the one who consistently cuddled and calmed their child, for example when the child fell. The mothers expressed that the experience of watching other people do what they wanted to do for their child was a

heart-breaking experience. In addition, some mothers indicated that having to rely on a third party led to feelings of humiliation or being a burden. This was because, while a mother desired to take care of her child, not only could she not take care of her child but also she needed a third party to take care of her and her child.

I believe it should be possible to find different ways for the mothers to engage and communicate more effectively with their child. As a design researcher, I believe that the products can create new opportunities for the mothers, but the first step is to reframe the way of looking at mothering with SCI. According to Johnston and Swanson (2006), the dominant way of mothering is a consequence of the social construction of a 'good mother.' As discussed previously, in Chapter 2, the stereotype of a good mother and the normative template push disabled mothers to become marginalised (Frederick, 2014).

The findings acknowledge earlier studies that show that the dominant able-bodied way of mothering is not achievable for all mothers (Daniels, 2019; Green, 2015; Lewis, 2002). In the disabling environment, disabled mothers encounter many difficulties in being accepted by society as capable mothers (Fitzmaurice, 2002; Grue & Lærum, 2002). According to Lloyd (2001), the traditional stereotype of mothering leads disabled mothers to prove their capability of mothering based on the social construction of mothers as able bodied. Consequently, this results in many mothers experiencing oppression and devaluation (Prilleltensky, 2003).

9.1.2 The effect of societal attitudes on the construction of meaningful mothering experiences

Traditionally, disabled women have been discouraged from becoming mothers and were seen by people such as family members, friends and health practitioners, as being incapable of looking after their children (Prilleltensky, 2003). The literature reviewed in Chapter 2 identifies how ideas of mothering are often constructed around able-bodied mothers who can independently carry out mothering tasks

(Fitzmaurice, 2002; Grue & Lærum, 2002; Guerin, et al., 2017; Malacrida, 2007). Stereotypes regarding disability have the potential to influence the experience of mothering more than the consequences of a mother's spinal cord injury.

As argued by feminist disability theory, disability is the outcome of the social exclusion of individuals who are not considered as able-bodied people. The social prejudice against people with disabilities excludes them from the society and results in disablism. The social prejudice against disabled mothers reinforces discriminatory attitudes towards them. Consequently, disabled mothers have to prove themselves as capable mothers (Malacrida, 2007; Nosek et al., 2001). As a result of disablism and prejudicial attitudes, disabled mothers lack confidence and are anxious regarding their ability to fulfil the mothering role (Thomas, 1997).

As discussed in Chapter 2, the modernist viewpoint of universal truth constructs the social standards and expectations of mothering that hinge on the notion of normality. Consequently, the stereotype of an able-bodied mother can marginalise disabled mothers in different areas, including the design of child-caring products. This approach can overlook the experience of mothers living with SCI, who do not 'fit the mould', and can lead to the marginal position of them to the design discipline. This dominant approach leads to unmet needs of users with different capabilities.

Garland-Thomson's (2011) concept of misfit, defined in Chapter 3, reframes the way of looking at the relation between the material environment and bodies. Garland-Thomson's concept of misfit challenges the way that disabled people have to adapt themselves to the material environment that is not designed and fit for them. According to my findings, the lack of 'fit' child-caring products the mothers were required to modify the existing products, such as baby cots and carriers, to fit their bodies (see section 5.1).

On the other hand, existing child-caring products are designed to fit able-bodied mothers, whose bodies are

considered as the reference in product design. Hence my study explored how the mothers living with SCI construct meaningful mothering experiences through child-caring products from the perspective of 'misfit'.

As a design researcher, looking at mothering through the lens of feminist disability theory and co-design helped me better understand that that there is not only one true way of mothering but, rather, diverse ways of mothering. Consequently, I believe that the integration of feminist disability theory and co-design can be used to extend the notion of diversity to the design discipline. Looking at disability as human diversity (Garland-Thompson, 2005) can help to deconstruct the portrait of an able-bodied woman as a real mother, thus providing equal access to resources and products for mothers with disabilities.

My findings highlight the limitations of access to child-caring products that could be used by mothers with SCI in Aotearoa New Zealand. This shows the impact of the normative approach in addressing the needs of these mothers, which can result in able-bodied mothers in becoming more privileged than mothers with SCI with regard to having their needs met. While there are a limited number of existing 'fit' products for mothers with SCI worldwide, the findings indicate that the mothers with SCI in Aotearoa New Zealand have more limited access to these products.

All the mothers in this study reported not being able to find a 'fit' child-caring product in Aotearoa New Zealand. Consequently, as I have shown in Chapter 5, these resourceful mothers have modified existing products to address their needs.

The lack of access to 'fit' products could be related to the Aotearoa New Zealand context. The average number of people that experience SCI in NZ is 80-130 people annually (New Zealand Medical Association, 2016). This limited number would not be profitable enough for investment in the manufacture or importing of products. In a capitalist economic

system, the mass production of products is based on market demand. Therefore, it is likely that the needs of the majority of users, as opposed to those of minority groups, will become targets for investment. This results in the marginal positioning of mothers with SCI and their unequal access to 'fit' child-caring products compared to the able-bodied. However, a product-service system such as a product loan centre or product library could pave the way to providing an equitable access to child-caring products for mothers with SCI and, more widely, for disabled parents (see section 9.4).

According to Mays (2006), systematic inequality for disabled women has historical, social and economic roots. Garland-Thomson (2011) considers, the inconvenient interplay of human variation and material environment can result in marginalisation.

My findings suggest that the design discipline largely addresses the needs only of able-bodied mothers. The way the design discipline is structured and the underlying epistemic principles it draws on have a serious impact on the mothering experience of women with SCI. The basic needs of mothers have been excluded because of their marginal position to the design discipline, including those of Hannah, Olivia, Sophia and Emma – who wish to access a product that could assist them to reach the floor to play with their child. Olivia and Sophia both dreamt to be the one who picks up their child from the ground and it was Hannah's desire to independently bathe her child.

This study found that an approach based on the 'normate template' (Hamraie, 2013) in product design marginalised many needs of mothers with SCI.

The epistemology of ignorance in the design discipline (Hamraie, 2013) leads mothers with SCI to face disabling societal and physical barriers (Hamraie, 2013). Findings from my research highlight that products that do not fit the needs of the mothers, and social expectations, can have an impact on the way the mothers construct their mothering experiences.

Several mothers in the research observed that, while there was a wide range of child-caring products for able-bodied mothers, there was limited access to 'fit' child-caring products for mothers with SCI.

9.2 How can product design improve meaningful mothering experiences in the home environment?

This section starts with a discussion of the integration of feminist disability theory and co-design as a lens to explore the needs of marginalised users. I then discuss the importance of desirability in accessible products for the mothers with SCI in Section 9.2.2.

9.2.1 The integration of feminist disability theory and co-design as a lens to explore the needs of marginalised users

Employing the co-design process provided me with better means to explore the mothers' meaningful mothering experiences. Through the co-design sessions, the mothers shared their mothering experiences and ideas by using generative tools such as card sorting, coloured stickers, drawing and making objects (see sections 4.2.3 and 4.2.4).

When I initiated the research, I aimed to improve meaningful mothering experiences by focusing on the interplay between mothers with SCI and child-caring products. Gradually, through the codesign sessions, I learned that I had to apply a wider perspective to address the mother's needs, rather than concentrating on child-caring products alone. This aligns with Stappers and Sanders's (2003) guidance that participants' stories can reveal useful information for designers in the co-design processes. By adhering to this, generative tools helped me to more effectively engage with the mothers' worlds. Every artefact that the participants made narrates a story of their experiences (Sanders, 2002).

Sanders (2002) claims that artefacts have a key role in informing a designer about the user's feelings, dreams and fears. As such, the co-design process was useful in providing

me access to the unmet needs of the mother that allowed me to be able to develop new insights. This ultimately led me to explore new opportunities through any product or piece of furniture in the home environment that might enhance a mother's interaction with her child, rather than focusing on specific child-caring products to improve meaningful mothering experiences. For example, I found that several participants loved the idea of a 'fit' recliner. From their perspectives, an accessible recliner would provide them with a new and safe opportunity to engage more with their child on the floor.

Through the use of card sorting and inspiration cards I had noticed that the mothers preferred to spend some time out of their wheelchairs, which was in contrast with my initial idea of designing a new wheelchair for the mothers to help to facilitate their mothering tasks. This highlights the role of codesign to guide a designer to be able to identify participants' needs. Consequently, the co-design process challenged my

initial concepts, thus allowing me to avoid perpetuating issues that I identified in the literature review.

The co-design process helped me to find out the mothers' own ideas about their experiences. By applying a participatory way of knowing in my research, I considered the mothers as the experts of their experiences and new design opportunities were generated based on the mothers' ideas and needs. In addition, feminist disability theory supports the establishment of a theoretical outline to better understand marginalised embodiments through historical and ideological perspectives (Garland-Thomson, 2011). Feminist disability theory looks at disability as a system that involves stigmatisation based on human diversity as a complex collection of diverse individuals. In doing so, the integration of feminist disability theory and co-design gave me the opportunity to conduct fair and two-way communication. Initially, the participatory approach of co-design provided a way for the mothers in this study to articulate more precisely and realistically what their

mothering challenges and meaningful mothering experiences were. According to Sanders and Stappers (2008), co-design refers to the "collective creativity as it is applied across the whole span of a design process" (p. 6). Through co-design sessions, I gained deep understanding of the mothers' experiences. In particular, the various generative tools helped me to explore the mothers' viewpoints from different aspects.

The application of generative tools, such as card sorting, coloured stickers, emojis, drawing and making objects, in Cycles II and III was useful to clarify the mothers' needs and experiences by helping to develop a shared language. These tools assisted me to explore the hidden aspects of the mothers' experiences, which might not have been able to be expressed easily in words.

Sorting cards, coloured stickers and inspiration cards were found to be evocative ways to enable the mothers to express their mothering experiences. This was because the mothers were able to share their ideas and experiences in tangible ways. Through these activities the mothers described their past experiences and generated ideas for the future. Drawing and making objects helped provide tangible ways of visualising and generating ideas. In addition, generative tools provided the mothers with different means to share their ideas and experiences. The process of selecting cards, coloured stickers, post-it notes, drawing and making objects generated valuable discussion on their mothering experiences and helped them to identify their priorities when undertaking mothering tasks. The generative tools were an effective way for the mothers to convey their emotional experiences, and discuss challenging activities and resourceful solutions.

Through these activities, the mothers shared their stories, fears, tears and laughter in relation to their experiences of mothering with SCI. The stories behind what the mothers created or the images they selected revealed significant insights for me. For example, in sorting cards the majority of the mothers began to sort the cards that included physical proximity and bonding.

During card sorting, the mothers explained their concerns and priorities regarding mothering activities. The most important mothering activities were related to attachment, including breastfeeding, kissing and cuddling, calming a child and physical proximity (see section 6.1).

The majority of the drawings and objects that the mothers made were about ways to create opportunities to more effectively engage with their child. Through the process of discussing and describing the ideas the necessary physical properties of a product were identified, as well as why these properties were important (see sections 7.1).

In the first research Cycle, I intended to explore the mothers' challenging activities and meaningful experiences by giving voice to the mothers as the expert of their experiences. Cycle I provided me with an initial understanding of the construction meaningful mothering experiences. Following this initial stage of the research, I aimed to explore new opportunities for the mothers through product design.

Through the co-design process in Cycle II, I engaged in an ongoing dialogue with the participants that enabled me to gain a deeper understanding of meaningful mothering experiences. The findings of Cycle II were useful to further develop ideas and themes, which then helped me to generate new concepts.

The subsequent co-design sessions in Cycle III assisted me to explore the ideas about what activities and situations were identified as meaningful by the mothers, and to validate the concepts that I had developed from the findings of the first and second cycles. The iterative research cycles helped me to give form to the mothers' experiences. Having validated the concepts, I was able to more effectively communicate my findings and develop concepts to prototypes in Cycle IV. Cycle IV aimed to give voice to the mothers and hear their feedback on the prototypes developed based on the findings of Cycle III.

The findings of Cycle IV indicated that a 'fit' product or piece of furniture had the potential to improve meaningful mothering experiences: a product or piece of furniture might change a

heart-breaking mothering experience to a ground-breaking experience. For instance, using the 'fit' recliner would create new opportunities for the mothers to have one-on-one interactions with their child on the floor by diminishing reliance on a third party on many occasions. Consequently, the heart-breaking experience of being an observer (the mother who observed other people engaging and playing with her child on the floor) could be turned to a meaningful experience of one-on-one interaction with her child on the floor. The recliner would be able to create a new opportunity for the mother to engage in a form of love language.

The integration of feminist disability theory and co-design assisted me to probe the effect of the stereotype of a mother as able bodied leading to the unmet needs of mothers with SCI. While all people have a right to the equal opportunity of access to products, according to this research the mothers with SCI have limited access to child-caring products that meet their needs.

As I discussed in Chapter 2, product design practice has mainly responded to the needs of dominant able-bodied users. Similarly, my findings acknowledge how the impact of design based on able-bodied users has resulted in overlooking needs of the mothers with SCI. For instance, according to my findings designers have developed new child-caring products, such as a nursing pillow for able-bodied mothers, but not a breastfeeding pillow that addresses the needs of mothers with physical disabilities; a jogging pushchair for able-bodied mothers who want to run, but not a pram for mothers in a wheelchair; or no product to facilitate the changing of nappies by disabled mothers. I believe that embracing an equity agenda to integrate mothers with SCI into the mainstream of product design would lead to more equal opportunities for disabled mothers.

A social-equity approach to design could help creating equal opportunities and combat discrimination by giving access to products that meet the mothers' needs. The integration of

feminist disability theory and co-design provided me with a lens to reimagine my role as a designer – becoming a creative facilitator who gives voice to the mothers' experiences rather than being an expert of the mothers' experiences. Consequently, I applied the integration of feminist disability theory and co-design as a magnifier to look for new opportunities to address the unmet emotional and physical needs of the mothers through products.

9.2.2 The importance of desirability in 'fit' products for the mothers living with SCI

Nowadays products have to provide users with more than usability (i.e. the quality of a product to perform a defined goal effectively) and functionality (i.e. the quality of a product's capability to accomplish a purpose well); they also need to meet users' emotional needs (Jordan, 2000; Norman, 2004). According to the concept of misfit (Garland-Thomson, 2011), the material environment, which includes products and environment, negative impacts on the experience of women with disabilities. Given that a user's emotional reaction to a product is not only related to aesthetic and functional aspects but is also connected to the user's pleasure (Green & Jordan, 2002), it can be concluded that a product should be both physically and emotionally fit for the user's needs. According to Desmet et al. (2001), 'emotionally fit' refers to products that "elicit the emotions that the user would like to experience" (p. 32). While designers have considered users' emotions extensively over recent decades, according to my research findings, the existing 'fit' products were considered to be less desirable by the mothers with SCI in this study.

Based on the findings of Cycle III, it may be inferred that most of the existing products in the market that are designed for mothers with SCI are designed to address their functional needs, and not their emotional needs. Findings highlighted that the mothers with SCI not only expected usability and functionality, but they also wanted desirability in a 'fit' product.

According to Norman (2004), desirability is related to the three levels of visceral, behavioural and reflective response. The visceral level is related to a product's appearance and aesthetics. The behavioural level is related to a product's function and a user's interaction with a product. The reflective level can be related to the construction of meaning by a user through a product, and thus refers to a user's reflection and the subjective factors that construct meaning through use of a product. For example, the mothers' feedback on products with medical characteristics was rooted not only in their emotions, but also it was related to their reflective response to the design. This was because products with medical characteristics conveyed illness to the mothers.

From the mothers' perspectives, a 'fit' product was not only defined by functionality, but also by the way the mothers constructed meaning with respect to being a mother through the use of a product. The way the mothers perceived themselves as a product user influence the construction of a meaningful experience. The 'fit' recliner designed through this research (section 7.3) was not perceived by the mothers as a medical product, and was viewed to be more in harmony with their home environments (i.e. aesthetically compatible). In addition, the 'fit' recliner what is perceived by the mothers as being able to remove certain physical barriers (i.e. inaccessible floor area, the functional aspect) and as a consequence provide them with the opportunity to engage with their child in a previously inaccessible space (i.e. meaningful experience).

According to Norman and Ortony (2003), the visceral and behavioural aspects of design are more controllable by the designer than the reflective aspect. Designers attempt to create meaningful experiences for users through form and function. However, emotional responses created by users depend on different factors, including the user's memory, background and society (Adelson, 2010).

The integration of feminist disability theory and co-design assisted me to potentially improve meaningful experiences by exploring the mothers' reflective level. For instance, through the co-design sessions, I found that a desirable product such as a 'fit' recliner, which addressed the mothers' aesthetic and functional needs, created pleasant emotions such as pride and achievement, but a functional product with medical characteristics created unpleasant emotions such as deficiency and illness.

The effect of the medical model of disability, with its focus on disability as a deficient functional impairment, in the design discipline may lead to the creation of products that are designed to functionally 'fix the impairment', instead of attempting to create meaningful experiences for disabled people. Consequently, there is a need for an epistemic shift in the design discipline (Hamraie, 2012) towards constructing new meanings of inclusion through the material environment and products for mothers with SCI.

Considering desirability in the design of 'fit' products would improve the way design addresses the needs of mothers with SCI. According to Newell and Gregor (2002), aesthetics can also enhance the effectiveness of products for disabled users with a disability by making the products more acceptable to them. Pullin (2009) suggests designers consider the aesthetics and style of prostheses and assistive products. From Pullin's (2009) perspective, eyeglasses are fashionable protheses. Pullin suggests designers create assistive devices with the same approach as they do when designing fashionable products. With this approach, the aesthetics and style of prostheses and assistive products would be as significant as the functionality of the products

Findings of another study on leg protheses for children in Cambodia acknowledge the important role of the aesthetic appearance of leg protheses for children with disabilities (Hussain, 2011). Similarly, my findings show that the visual characteristics of products impacted on the mothers' interest

in using a product. All the mothers in this research emphasised the importance of using products that are in harmony with their home decor, rather than products with medical characteristics (e.g. hospital bed, walkers etc.). The mothers considered that products with medical characteristics made their homes feel institutionalised.

From the mothers' perspective, their home was a place in which they wanted to feel safe both emotionally and physically. Gurney (2000) defines home as "an emotional warehouse wherein grief, anger, love, regret and guilt are experienced as powerfully real and, at the same time, deposited, stored and sorted to create a powerful domestic geography, which, in turn sustains a complex and dynamic symbolism and meaning to rooms and spaces" (p. 34). Tanner et al. (2008) also see the home environment as more than a physical building. They see that the home includes physical, social and personal experiences. While, the physical environment consists of bricks, materials and the physical structure of the building, the social experience consists of the relationships between the people in the home environment (such as family members and friends). The personal experience reflects an individual's lifestyle and feelings, such as intimacy, safety and belonging.

According to Deleuze and Guattari (1987), assemblage is a continuous process of connectivity between heterogeneous elements. The connection between the elements is not a fixed structure, and the elements can be replaced for a particular relation and affect. "We will call an assemblage every constellation of singularities and traits deducted from the flow – selected, organized, stratified – in such a way as to converge (consistency) artificially and naturally; an assemblage, in this sense, is a veritable invention" (Deleuze & Guattari, 1987, p. 406).

Deleuze and Guattari (1987), consider that home assemblages are more than collection of objects; they contain a specific language and meanings. Consequently, I suggest the home as

an assemblage of the mother, the child and 'fit' products contains a love language and mother-child relationship. The research findings confirm that 'fit' products and furniture in their home would provide the mothers with a space to communicate with their child in their love language and help to sustain the mother-child relationship. This is because 'home' as an assemblage is "not a pre-existing space; it is not the house [itself]. [Rather,] it is the continual attempt to create a space of comfort for oneself, through the arrangement of objects, practices, feelings and affects" (Stivale, 2014, p. 93.)

Similarly, Garland-Thomson's (2011) concept of 'misfit' describes the interaction of disabled bodies with the material environment. As discussed in Chapter 3, Garland-Thomson's concept of misfit (2005) sheds light on how an incongruent arrangement between a body and the material environment leads to disability. Thus, an inconvenient connectivity between people and the material environment can result in the marginalisation of those who do not fit. My findings highlight the way 'fit' products, furniture and the home environment can trigger different emotions such as happiness, comfort, deficiency, exclusion, illness, inclusion and safety. For example, my findings show how the meaning of 'home' is constructed through the mothers' self-concepts. The meaning of home was linked to their interactions with people, products and their child in the home. In other words, home was a representation of the mothers' lifestyles and interactions.

9.3 Contributions of the research

In the previous chapters (5, 6, 7 and 8), I have presented the findings that emerged from the four research cycles. Since a thorough analysis of the findings and their potential interpretations have been presented in these previous chapters, in this section I provide a brief summary of my analysis and situate it in existing literature in order to discuss the contribution of this research to existing knowledge.

9.3.1 The potential of products to construct meaningful mothering experiences with SCI

The findings of this research contribute to our current knowledge of the potential of products that might facilitate meaningful mothering experiences for mothers living with SCI. While some of my findings support the results of earlier studies, new findings have also emerged that add to what is known in the existing literature.

The results of this study highlight the way stereotypes and social exclusion affect the experience of mothering with a disability, as identified by Guerin et al., 2017; Kaiser et al., 2012; Payne and McPherson, 2010; and Shpigelman, 2015. According to my findings, the stereotype of an able-bodied mother affected the mothering experiences of those with SCI, and resulted in their social and material exclusion.

Frederick (2017) argues that earlier studies on mothering have been mainly focused on able-bodied mothers. The modern ideology of motherhood, which concentrates on 'normal' standards, results in the stigmatisation of disabled mothers. The modern ideological view of disabled mothers results in these mothers feeling that they are incapable of meeting the average standards of society in mothering (Malacrida, 2007; Shpigelman, 2015; Frederick, 2017).

Findings from this research confirm those of previous studies (e.g. Thomas, 1997; Grue & Lærum, 2002; Malacrida, 2009; Frederick, 2015, 2017), that normalcy causes disabled mothers to be stigmatised.

Several studies report the impact of stigmatisation on disabled mothers and their construction of identity. According to these studies, the stigmatisation of disabled mothers creates psychosocial challenges for disabled mothers (e.g. Prilleltensky, 2004; Shpigelman, 2015; Frederick, 2017). For instance, Craig and O'Dell (2011) consider that a normative

approach to mothering results in the construction of 'othered' mothers. Consequently, mothers who do not fit the stereotype of a 'good mother' perceive themselves as 'others.' The construction of 'othered' mothers can lead to the social exclusion of disabled mothers and separate them from the dominant mothers to being the marginalised mothers, where mainstream social norms do not apply to them. My research findings highlight that the mothers' stigmatisation has led to a separation between able-bodied mothers, who are physically able to undertake and complete all mothering tasks independently, and the disabled mothers who perceive themselves to be outside this image. The majority of the mothers in this research considered the social construction of the able-bodied mother as the reference definition of a capable mother. Consequently, several mothers considered that they felt the need to prove their mothering capabilities as a result of feeling being judged by others.

According to Forcey (2001), "mothering is a socially constructed set of activities and relationships involved in nurturing and caring for people" (p. 157). From Forcey's perspective (2001), the notion of mothering is a social construction that is internalised by women as a mandatory way of mothering within their society.

Feminist studies challenge theories that apply essentialist approaches to women that constrain the position of women to biological imperatives (Glenn, 2016; Kerrick & Henry, 2017; Miller, 2007; Tardy, 2000; Choi et al., 2005). D'Arcy et al. (2012) argue that an essentialist approach to mothering has a negative impact on women's lives. This is because patriarchal social constructions rooted in essentialism constrain women's ways of mothering. D'Arcy et al. (2012) highlight that postmodern feminists acknowledge that women's diversities, such as race, age, colour, sexuality and disability, also influence their experiences of mothering. Feminist scholars shed light on the importance of cultural

values, social constructions and human diversities in mothering (e.g. Collins, 1987; Edin & Kefalas, 2005; Lareau, 2003).

Feminist scholars shed light on the importance of cultural values, social constructions and human diversity in what constitutes mothering (e.g. Collins, 1987; Edin & Kefalas, 2005; Lareau, 2003). According to sociocultural anthropology studies, mothering consists of flexible and improvisational activities (Barlow & Chapin, 2010). As a consequence, many sociocultural studies on mothering have challenged the essentialist viewpoint of early mothering studies. In part, this is because the majority of these early studies (e.g., Briggs, 1970; Erikson, 1950; Kardiner, 1945; Whiting & Whiting, 1975) neglected the diverse aspects of mothering. Consequently, the essentialist studies on mothering lead to viewing a mother as a subject whose purpose is to address the needs of her child.

Barlow and Chapin (2010) argue that not only social construction and cultural beliefs, but also psychological recommendations in mothering regarding child development, such as being patient, protective and nurturing, can reinforce the stereotype of a 'good mother.' Similar to Barlow and Chapin (2010), Phoenix and Woollett (1991) argue that psychology scholars focus mainly on 'ideal' mothering, which differs from the real experience of many mothers. Thus, psychologists' recommendations regarding child development can, by overlooking human diversity and individual identities, constrain the way a mother perceives herself as a mother. Previous studies show that the idealisation of mothering leads mothers to lack confidence in the quality of their mothering (Perälä-Littunen, 2007; Kerrick & Henry, 2016).

Chodorow (1994), an early feminist psychologist and sociologist, argues that women, in studies related to the mother-child relationship, must be viewed as ''self, actor, agent, experiencer'' (p. 4). Chodorow's perspective on the

mother–child relationship is useful to help researchers to avoid the objectification of mothers in related studies. In my research, the integration of feminist disability theory and co-design assisted me to uncover the impact of social constructions on the mothering experiences, by helping me consider the mothers as the experts of their experiences.

The research findings of my research highlight that not only do social constructions require the mothers to fit their way of mothering to the dominant construction, but the mothers also have to fit themselves to a material environment that was designed for able-bodied people. By expanding our understanding of the potential of products to be able to construct meaningful mothering experiences for those mothers with SCI, we can gain a deeper understanding of how products could create new opportunities for disabled mothers. We can also then identify products that have been developed with insufficient attention to address the needs of users with disabilities.

My study confirmed the findings of earlier studies (e.g., Mitra et al., 2017; Powell et al., 2019; Wint et al., 2016) that products play a significant role in facilitating mothering activities. According to my findings, products may assist mothers with SCI to more actively participate in a greater variety of mothering tasks. Similar to the above studies, my findings acknowledge that the mothers in this research wanted greater access to products that better met their needs.

My research shed light on the mothers' lack of access to child-caring products that may help them to fit themselves to the material environment. Due to the lack of 'fit' products, the majority of the mothers in this study applied a range of modifications to existing products to help facilitate their mothering activities (see section 5.1).

The research findings also support previous findings showing that there is a difference between physical mothering activity and a meaningful mothering experience. Similar to Olsen and Clarke (2003) and Kaiser et al. (2012), my study acknowledged

the importance of emotional interaction and bonding to construct meaningful parenting experiences. Emotional activities such as one-on-one engagement, communication and bonding were identified through this research as more important to the mothers than practical activities (i.e. changing a nappy or dressing a child). Furthermore, my study supports previous findings that physical proximity has a significant role in mother-child bonding (e.g. Bitchener & Storch, 2016). From the mothers' perspectives, physical proximity such as calming, breastfeeding, cuddling and kissing their child forms the mother-child relationship and helps the mothers to feel connected to their children. According to research findings, products have a potential to create new opportunities for the mothers to improve their mother-child bonding.

My study explored the experience of the mothers with SCI from a new perspective. Most previous research explored the impact of physical or social barriers on the experience of parenting, or mothering, with disabilities (e.g. Daniels, 2019; Guerin et al., 2017; Kaiser et al., 2012; Malacrida, 2007; Reid, Angus, McKeever, & Miller, 2003; Wint et al., 2016). My research took a different focus by exploring the role of products on the construction of meaningful mothering experiences for those mothers living with SCI.

In this research, the difference between physical mothering tasks and meaningful mothering experiences (i.e. frequent and consistent one-on-one interaction and mother-child bonding) was an important theme. There was little evidence of previous research that explored the role of products to create new opportunities for mothers with SCI to interact with their children. I was surprised to learn how different products (and often seemingly simple) could significantly improve meaningful experiences for the mothers with SCI in this study by providing them with new opportunities to express their love for their child. For example, I found that the idea of the 'fit' recliner was perceived not only as a design solution to help mothers physically go down to the ground, but also could

provide a mother with moments and occasions for an emotional connection with her child, which would help to further build mother-child bonding (see section 8.1).

The idea of the recliner also help to shed light on the way in which products may affect the mothering experiences of those living with SCI. The recliner is a tangible example of how the mothers' unmet needs may be met through product design. The recliner as an example of how a 'fit' product highlighted how physical connection between a mother and her child could also create emotional connection between them.

By exploring the idea of a recliner also revealed how a short physical distance between a mother and her child (from a mother's wheelchair to the ground) can influence the construction of meaningful mothering experiences. From the mother's perspective, physical proximity and one-on-one engagement with their child was an important way to communicate with their child and express their love. Hence, the distance between a mother's chair to her child's level (i.e.

an inaccessible floor), while may appear insignificant to an able-bodied person, was perceived as a significant and important distance that separated a mother from her child. While a mother and her child live together in the same environment, an inaccessible floor effectively resulted in them living in two different levels and spaces.

Drawing from Deleuze and Guattari's concept of assemblage (1987), Gibson et al. (2017, 2014, 2012) studied the effect of temporary connectivity of heterogeneous components (i.e. bodies, social meanings and technologies) in disability contexts. The results of these studies highlighted that while a particular assemblage has an enabling effect in a particular context, the same assemblage can be disabling in another context. Similarly, my findings highlight that while the assemblage of the mother, the child and her wheelchair enable a mother to move around her home with her child, the same assemblage was disabling when the mother needed to sit on the floor and play with her child. Consequently, the

assemblage of the mother, the child and her wheelchair could be replaced with a new assemblage of the mother, the child and the 'fit' recliner, to provide the mother with an opportunity to go down to the floor and spend time with her child there.

According to Anderson and McFarlane (2011), "Assemblage appears as a specific form of relational thinking that attends to the agency of wholes and parts, not one or the other" (p. 162). For example, findings from my research show that although the assemblage of the mother, her caregiver and the child facilitated mothering activities, the same assemblage limited opportunities for one-on-one interaction and bonding between a mother with SCI and her child. This was because, for several mothers, the permanent presence of a third party was perceived as a threat to their mother-child relationship. In this case, a new assemblage of the mother, the child and the recliner may create a new opportunity for one-on-one interaction between the mother and the child. As a result, a new assemblage (consisting of the mother, the child and the recliner) may lead to the construction of more meaningful mothering experiences. However, the same assemblage is also disabling, as it would not allow the mother to move around the house.

Given that "An assemblage is a becoming that brings elements together" (Stivale, 2014, p. 91), the assemblage of a mother, a child and 'fit' products can be dynamically becoming, and replaced with other assemblages consisting of a mother, a child and an 'fit' product (e.g., a recliner, soap holder, baby carrier, cot) for a particular effect. The variety of assemblages between a mother, child and different product/s could provide a mother with SCI with more occasions for one-on-one interactions with her child, which would result in more meaningful mothering experiences in the home environment.

Given that the needs of minority groups are neglected as a result of a normative approach (Garland-Thomson, 2011; Hamraie, 2012, 2016; Reimer, 2016), helping product designers to be more aware of the potential for 'fit' products to

create new opportunities for users with disabilities. As such, it is hoped that this research may lead designers to be more concerned about disabled users unmet needs and ultimately result in the creation of more meaningful experiences through appropriately designed products.

9.3.2 Using a product instead of relying on a third party

According to the research findings (Chapters 6, 7 and 8), the mothers with SCI would prefer to use a product instead of needing to rely on a third party (i.e. the mother's caregiver) for mothering activities. The permanent presence of a third party negatively impacted the construction of meaningful mothering experiences for the mothers. Data highlighted that one-on-one interactions between a mother and their child strengthen the mother-child bonding. However, the need to rely on a third party to perform mothering activities was seen to threaten the bonding between a mother and their child. Consequently, the potential opportunity for a product to diminish the need of the permanent presence of a third party and provide the mothers with more occasions to engage with their child was seen as a significant development (see section 6.3).

Few studies that have explored the impact of products on the experience of disabled parents. Most previous research has placed emphasis on accessibility and the role of products to facilitate mothering tasks (Daniels, 2019; Frederick, 2017; Powell et al., 2019; Shpigelman, 2015; Tefera et al., 2017). Most of the products that were considered in these studies included products and resourceful solutions that disabled parents had applied themselves to modify both existing products and their home environments (e.g. adapting a cot or baby sling, placing needed items such as wipes and diapers in different rooms, using a desk or kitchen table to change a nappy and having lower kitchen cabinetry and sinks).

My findings highlight how mothering activities are considered a love language for the mothers to communicate with their child. As it is for able-bodied mothers, motherhood is a

significant aspect of the life course for disabled women (Shandra et al. 2014). Findings from my research are consistent previous research (Powell et al. 2019; Thomas, 1997) that demonstrates that a third party performs a facilitator role for disabled mothers in mothering activities. However, the permanent presence of a third party limited the opportunities for the mothers in this research to communicate with their child in their love language. Thomas (1997, p. 637), uses the term ''unhelpful help'' for people (e.g., caregiver, midwife, GP and friends) who are "hopeless," "fussing," "over-protective" or "taking over" a mother's role while helping mothers with disabilities. Similarly, while the majority of the mothers in my research acknowledged the helpful role of their caregivers to facilitate their mothering activates, they considered that the permanent presence of a third party constrained the occasions for one-on-one interaction between them and their children.

According to Prilleltensky (2004), "independence is more about freedom to make important life decisions and have control over daily routines. It is also about the right to decide what assistance is needed, how and when will be delivered and by whom" (p. 16). More specifically, my findings indicate that 'fit' products, by creating new opportunities for the mothers to have one-on-one interactions with their child, could enhance the mothers' control over their mothering; thus shifting the mothers' perceptions of 'being a care-receiver' to 'being a caregiver' (see section 7.1).

For the majority of the mothers in this study, being a care-receiver led to the construction of mothering experiences that were frustrating and humiliating. This led to feelings of being observed, or being limited to the role of observer: seeing others caring for her child. According to my findings, replacing a third party with a product would open up new opportunities to expand the relationship of a mother with SCI with her child.

9.3.3 Giving a voice to marginalised users

As discussed in Chapter 2, previous literature identified that there was broad interest to seek new approaches to improve users' experiences through design. For example, empathic design (McDonagh-Philp & Lebbon, 2000) intends to provide designers with better empathy with users, cultural probes (Gaver, Dunne, & Pacenti, 1999) are used to gain insight into users' values and culture; a tool PrEmo (Desmet, 2002) is used to investigate users' emotions about products and Kansei engineering (Nagamachi & Lokman, 2016) aims to translate user emotions to product specifications.

While current design methods are useful to provide rich insights into users' experiences, my findings align with earlier studies (e.g., Code, 1991; Garland-Thomson, 2002; Hamraie, 2016), which acknowledge that the epistemological position of designers results in the marginalisation of disabled people through the material environment. Consequently, there may be a greater opportunities to improve products for disabled people if designers were to reframe their epistemological position. According to Hamraie (2012), designers consider able-bodied people as the 'normate template' in architecture and design. This normative approach to design has led to the ongoing exclusion of minority groups (Garland-Thomson, 2011; Hamraie, 2016; Titchkosky, 2011).

Given that feminist qualitative studies aim to give voice to women in order to make changes for women (e.g. Adair, 2008; Collins, 2000; Lennie et al., 2003), in this research, I applied the integration of feminist disability theory and co-design as a way to give space to the mothers' voices in order to build collaboration between the mothers and myself as a design researcher, to bring their ways of knowing into the construction of meaningful experiences through products.

I used feminist disability theory with the intention of enhancing co-design as a method of exploring with women, by women and for women, and incorporated it with women's

ways of thinking, knowing, and doing (Code, 1991; Hidayat, 2018). Feminist disability theory assisted me to better explore the construction of meaningful mothering experiences by giving voice to the mothers; thus, centring the mothers as the knower of their mothering experiences through the co-design process.

The integration of feminist disability theory and the co-design method benefited the aims of my research as it provided me with a more detailed exploration of what constituted meaningful mothering experiences with SCI through a democratic way of knowing. Considering my feminist position, I believe that historical, cultural and social context has a significant impact on the construction of meanings (Hesse-Biber, 2007). Feminist disability theory (Garland-Thomson, 2005) provided me with a lens to better understand the influence of social constructions on mothers' subjective experiences in relation to mothering with SCI.

Moreover, applying feminist disability theory through an iterative co-design process provided me with a lens to focus on the influence of gender and disability on the way the product design practice has addressed the needs of the mothers in this study. As a result, I found that the social construction of an able-bodied mother has resulted in the marginalisation of the mothers with SCI within the design discipline.

My research highlights how people from minority groups may often have to take matters into their own hands, in order for their needs to be met. In the case of the mothers in this research, this was needing to modify existing products in order for them to be able to undertake their mothering tasks although many of the mothers resourcefully modified products to create more effective solutions to their needs, some still reported frustration over the lack of 'fit' child-caring products for purchase.

The literature shed light on the lack of products to meet the needs of disabled mothers (Alexander, Hwang, & Sipski, 2001; Daniels, 2019; Kaiser et al., 2012; Reid et al., 2003). These findings help show how minority groups may often face discrimination from the design discipline. This is because the user referent has been constructed historically on able-bodied people. Consequently, able-bodied users are often considered as a representative of all users in the design process and disabled users are marginalised through the design discipline (Hamraie, 2012, 2016). While it is probable, that this was not an explicit intention of a specific discipline, and is likely the result of how society constructs the value of providing product solutions for those in majority groups, the consequences for the mothers in the study are the same regardless.

My findings were similar to those of prior studies (Code, 1991; Garland-Thomson, 2011; Hamraie, 2016; Hidayat, 2018), and highlight the way a researcher's epistemological position significantly influences their research approach (i.e. how we know what we know). Findings from my research acknowledge that discrimination can occur through the way of knowing users' needs and experiences, in which users' opportunities to participate in the design process can be diminished by the dominant group of users (i.e. able-bodied mothers). Consequently, minority groups (i.e. the mothers in this study) have to fit themselves to existing products instead of having access to products that fit their needs.

Hearing marginalised users' voices in the design process may result in the construction of a material environment and products that are of benefit to the whole of society. In addition, giving voice to marginalised users may enable minority groups by providing them with a material environment that meets their needs, increasing the potential to pave the way to enhancing their social inclusion.

The integration of a co-design method and feminist disability theory also helped make visible some aspects of meaningful mothering experiences with SCI that were previously invisible

to me as a researcher. For example, through co-design with the mothers, I learned that the limited opportunities for one-on-one interactions between a mother and her child was perceived as a heart-breaking mothering experience, and importantly products had the potential to turn this heart-breaking mothering experience to a meaningful experience for the mothers in this study.

Physical prototypes helped make the whole process of co-design more meaningful for the mothers (see section 8.2). For example, all of the mothers in Cycle IV of the co-design process considered that a physical prototype as a tangible outcome (i.e. prototypes of a recliner and an ottoman) helped them to better understand the purpose and outcome of the activities done through the whole co-design process; hence, they found the whole co-design process to be meaningful and interesting. All the mothers mentioned that the physical prototypes of a recliner and an ottoman better clarified the application of generative tools (i.e. sorting cards, drawing, post-it notes and making objects) through the co-design process.

My study also demonstrates how generative tools (Sanders, 2000) were useful to translate the mothers' needs into physical product properties. This was because generative tools assisted the mothers to express and share their mothering experiences through a variety of creative activities such as sorting cards, drawing and making objects.

As discussed earlier, I applied feminist disability theory to enhance the co-design method by giving a voice to marginalised users from the early stage of the design process. Whereas the aim of co-design is to give a voice to users, it seems that its focus on object-making and participants' hands-on activities result in the exclusion of some 'bodies' as a consequence of some of the generative tools that might be used in codesign processes.

The emphasis of co-design on making objects with participants intends to use a new language to better explore users' hidden needs and experiences (Sanders, 2002). While this approach can be useful to better identify users' needs and dreams, the focus of co-design on object-making by participants can marginalise some users in minority groups. For example, because object-making is a challenging activity for some users, such as people with dexterity difficulties, blindness or double hand amputations their participation in such activities may be restricted, or not possible. The emphasis by co-design literature on object-making highlights the impact of the social construction of dominant users (i.e. able-bodied users) on the way design seeks to understand the needs of users.

Feminist disability theory, by concentrating on human diversity and people's differences, provided me with better insight into how I might revise activities to better suit the mothers' physical abilities. For example, in my research I applied a variety of activities such as card sorting, inspiration cards, post-it notes, coloured stickers, emoji stickers, drawing and making objects with different materials. I intended to offer the mothers different choices based on their interests and physical abilities.

In this research, two mothers had dexterity difficulties. Both mothers had difficulty with object-making. Therefore, I modified my strategy for these mothers and, instead of these participants making objects, they were able to explain their concepts and guided me to make objects based on their ideas. We also used other generative tools based on the mothers' choices. In co-design activities using tools such as coloured stickers and emojis, the mothers chose the coloured stickers and emojis and I pasted them on the paper. All the mothers in the co-design sessions were wheelchair users, so I placed all the co-design materials within easy reach for them.

In Cycle II, I held individual co-design sessions with the mothers, because some mothers lived in different cities and could not easily travel to Auckland. Consequently, I travelled

to the location of their choice for the individual co-design sessions. Given that I intended not to influence each mother's thoughts and ideas with my own perspectives, or interpretations, I shared the other mothers' thoughts and suggestions after I heard an individual's ideas. Then we discussed or generated further ideas based on the other mothers' thoughts and concepts.

In the co-design sessions with the mothers, I listened carefully to everything they said. Also, as a design researcher, it was my role to facilitate the co-design sessions, to support the mothers to share and express their mothering experiences so that they could actively participate in the co-design process (Lee, 2008). I found that as a facilitator of the co-design sessions, respect for the mothers' choices in co-design activities helped me to communicate more effectively with them. I found that in many cases it was best not to interrupt a mother to ask a question or persuade her to do a specific activity, but, instead, give her space to share her experiences in the way that she preferred.

According to my findings, the integration of feminist disability theory and co-design would be helpful for design practitioners and theorists to improve strategies to centre marginalised users. The integration of feminist disability theory and co-design could provide design practitioners and theorists with a new lens to concentrate on the experience of marginalised users and avoid an able-bodied approach to design. This would help pave the way to give greater voice to marginalised in design processes.

To summarise, I applied an integration of feminist disability theory and co-design, which the design and health research literature has not previously explored in relation to the potential of products to construct meaningful mothering experiences with SCI. The integration of feminist disability theory and co-design assisted me to better explore the role of products in the construction of meaningful mothering experiences with SCI.

9.3.4 Exploring the mothers' meaning construction through products at the reflective level of design

Eliciting positive emotions that users like to experience is a key aim in product design (Desmet et al., 2001). There are various studies about exploring users' emotions, and how products and systems may evoke emotions in users, and how these emotions can be better understood (Alaniz & Biazzo, 2019; Desmet, 2018; Francalanza et al., 2019; Uzun & Yıldırım, 2018). Norman (1988, 2004) have extensive studies on the concept of 'emotional design.' As previously mentioned, Norman describes emotions as having visceral, behavioural and reflective levels (Norman, 2004; Norman & Ortony, 2003).

The integration of feminist disability theory and a co-design method assisted me to explore the mothers' emotional connection and mothering experiences through products at Norman's reflective design level. This was important because it helped provide me with better understanding of the role of the mothers' reflections and their subjective experiences on meaning construction through products. Hence it was helpful to highlight the importance of 'how we know what we know' as a designer to elicit appropriate emotions through products for the mothers. According to my findings, a design approach that integrates feminist disability theory and co-design has much more potential to result in desirable product design. For example, I had anticipated that the aesthetics (i.e. visceral level) and usability (i.e. behavioural level) of 'fit' products would play decisive roles for the mothers, but through my research I learned about the deeper layers of the mothers' reasons behind their interest in using products (i.e. reflective level). The integration of feminist disability theory and co-design has resulted in a range of insights on translating the mothers' needs to product properties that were unlikely to be explored if I had applied each in isolation. I found the integration of feminist disability theory and co-design as a new

way of looking at product design and the mothers' meaning construction at the reflective design level (i.e. self-image).

According to findings, the mothers' meaning construction of a product was influenced by the way they perceived themselves as users of a product. Findings from my research highlight that the mothers' emotions played a key role in designing a 'fit' product.

Findings from my research highlight that product desirability is a decisive factor for the mothers. From the mothers' perspectives, products with medical characteristics lead to the meaning construction of them being ill or excluded from able-bodied groups. There is a big difference between a useful 'fit' product and a desirable 'fit' product: a useful product is designed to address the mothers' physical needs, but a desirable product meets the mothers' emotional and physical needs together. Through my research I found that a desirable product constructs a sense of inclusion and capability instead of a sense of exclusion and illness. From the mothers'

perspective, the sense of inclusion brings emotional value to a product. The integration of usability and desirability were the main factors in their willingness to use a product.

9.3.5   Limitations of the research

Through my research, I was able to get more insight into the construction of meaningful mothering experiences with SCI, and the potential of products to create new opportunities for the mothers. Nevertheless, there were some limitations in this research, which are discussed here.

As I explained in Chapter 4, my decision to include both paraplegic and tetraplegic mothers in all of the cycles was due to my need to get sufficient participants to ensure the reliability of my study and findings. It is important to acknowledge that paraplegic women had a broader range of abilities than the tetraplegic women. Because their level of spinal injury is lower their ability to carry out more mothering tasks is possible. For example, they were able to feed their child, change nappies,

and able to wheel their chair. In comparison, the two tetraplegic women required more assistance to change nappies and clothe their child. Also, they were more reliant on their support workers to pick up their child from the ground.

Co-design calls for the sessions to be done in a group setting. Such sessions with a mixed group of participants can yield rich results (Kankainen et al., 2012) in that they can bring different perspectives from participants to inform design and innovation direction. However, as explained in Chapter 4 my circumstances meant that Cycle I & II were carried out individually. These were useful to give equal voice to both the tetraplegic and paraplegic mothers, and hear their needs and priorities separately through the process of data collection and analysis. To overcome this working separately in the individual sessions, I shared the other participants' ideas and experiences. At the beginning of each individual co-design session, I shared what the findings from other individual co-design sessions (while considering participants' privacy), and

I asked for the participants' insights and feedback on these. This helped us to discuss, develop and generate ideas around what others had thought and suggested. What surprised me was that while there were differences in the abilities of the paraplegic and tetraplegic women, their priorities were the same. The main difference between the mothers was their physical abilities for tasks requiring fine motor skills. The paraplegic mother had no dexterity difficulties but the tetraplegic mother had dexterity difficulties in mothering tasks that needed using fingers such as changing nappies, clothing a child and closing buttons. In addition, the paraplegic mother was able to maintain her balance while bending and picking up a child from the ground but the tetraplegic mother was not able to maintain her body balance to bend and pick up her child from the ground.

Cycle II showed that all the mothers had similar priorities with respect to their mothering activities. The first priority of all the mothers was bonding (see section 6.1). Since, in this research,

the priority of both tetraplegic and paraplegic mothers was the same, the priority of the tetraplegic mothers was not excluded or marginalised by paraplegic mothers through the co-design process.

Another challenge was the need to combine tetraplegic and paraplegic mothers in Cycle III's focus groups. While it would have been preferable to split the co-design workshops based on the mothers' levels of spinal cord injury, due to the limited number of tetraplegic mothers in Cycle III (one participant), tetraplegic and paraplegic mothers were grouped together in the same workshop. At this time, combining tetraplegic and paraplegic mothers was thought likely to be challenging, as these mothers had different physical abilities, which might influence their needs and priorities as well as their ability to engage in the co-design tasks.

In our co-design session the tetraplegic mother was able to sort cards and sign her consent form but she was not able to draw and make objects. Consequently, we used activities that were usable for both mothers. The co-design activities included sorting cards, concepts and inspiration cards. For instance, in the group session, I used two types of card activities including sorting cards and inspiration cards. I used card sorting to identify the mothers' viewpoints on the characteristics and specifications of 'fit' products. Both mothers were able to sort cards by themselves. I also used inspiration cards. Through few words on inspiration cards, I aimed to prompt the mothers to describe their experiences and ideas. Both mothers actively shared their experiences and ideas, and developed each other's ideas verbally. In the workshop, instead of asking the mothers to draw and make objects, based on the mothers' ideas, I made objects to help bring their ideas into shape so that they could be compared and discussed alongside the other mother's. I applied this strategy to avoid the tetraplegic mother perceiving herself as 'other' in the workshop.

In addition, in Cycle IV, I conducted one-on-one interviews with the mothers to hear their feedback on the concept of a

'fit' recliner and our co-design process. According to the findings of Cycle IV, the tetraplegic mother who participated in the group co-design workshop expressed her satisfaction with the concept of a 'fit' recliner and our co-design process. The mother's feedback helped me feel assured that her voice and priorities were accurately represented in the research.

The second limitation of my research was that my study was limited to white European mothers with SCI. I attempted to recruit Māori mothers with SCI in my research. However, despite my efforts, I was only able to identify one potential Māori mother, who declined to participate in the research. The participation by Māori could enrich my research findings by including Māori culture and its construction of meaningful mothering experiences for those Māori mothers with SCI. In addition, the participation of Māori mothers could provide me with better understanding of the similarities and differences between Western culture and Māori culture in relation to the experience of mothering. Hickey and Wilson (2017),

challenge dominant cultural viewpoints to disability. They believe that the Indigenous perspective of disability has been neglected in Aotearoa New Zealand. According to Goodley (2016), the integration of disability and race constructs colonised societies. Consequently, the intersection of disability, gender, race and social class results in cumulative discrimination (Goodley, 2013). Meekosha (2011) claims that people from diverse cultures interpret disability differently. Thus, the relational and collective viewpoint of Māori culture, as well as Pacific Island, African and Asian cultures, could challenge, extend and enrich my findings.

While having a specific focus with specific participants allowed me to deeper explore my research questions, I acknowledge that the research conclusions may not apply to all mothers with SCI and their experiences with products.

Finally, given that my research aim was to explore the construction of meaningful mothering experiences with SCI through products and I did not intend to investigate the

functionality of a product to facilitate mothering activities with SCI, consequently, I did not make a functional prototype of the 'fit' recliner. This stage of the process could still be carried out in order to make a functional prototype and carry out the necessary testing in the future.

9.4 Future work

Three areas can be identified for future work. From the research findings and the mothers' feedback in Cycle IV on the concept of a 'fit' recliner, I consider the implementation of a 'fit' recliner as the first direction for future work.

As discussed earlier, the findings of Cycle IV highlighted the mothers' interest in the concept of a 'fit' recliner as a new opportunity to construct a meaningful mothering experience. The mothers' enthusiasm for the concept of a 'fit' recliner motivated me to explore more deeply the feasibility of the concept implementation. To do so, I had two meetings with mechanical engineers about the feasibility of making the

prototype of a 'fit' recliner. According to the meetings, the 'fit' recliner is a feasible concept. Based on the initial estimates, making a functional prototype would cost $3000.

I had also a discussion with a marketing manager of a local furniture manufacturer. While the marketing manager admired the idea of a 'fit' recliner, she suggested that the organisation was unlikely to be a suitable partner for my idea, as they had a wide range of different chairs that addressed the needs of their customers. Her response reminded me of the normative approach in product design, which leads to the marginalisation of disabled users such as mothers with SCI. Since the limited number of users would not be profitable enough for investment in the manufacture of a 'fit' recliner, I reflect that a likely path to implementation may be via financial support from philanthropic organisations (e.g., United Way). I plan to have meetings with the Accident Compensation Commission (ACC), and similar support organisations, to explore the potential of funding resources to

produce a 'fit' recliner, and explore how it might be made accessible to potential users, including the mothers in this research.

It should also be noted that testing the function of a 'fit' recliner and hearing the mothers' feedback on the functionality of the prototype would be an essential part of developing the 'fit' recliner. Consequently, ethics approval for testing the functionality of the recliner will be necessary for any ongoing development.

A second direction for future research could be the exploration of strategies in product design practice to reinforce the use of customised design to better support disabled mothers/ parents rather than focusing on the developer manufactured products. As discussed in Chapter 2, manufactured products apply essentialist standards in which an able-bodied person is considered as a design referent (Hamraie, 2012; Imrie, 2012). My findings acknowledge that product design based on able-bodied users has led to overlooking the needs of the mothers with SCI. Consequently, exploring new strategies that aim to design based on body variations rather than applying essentialist standards would pave the way to designing a material environment that fits all of us.

Findings from my research have encouraged me to propose a product-service system for mothers/parents with SCI as a final direction for future research. The following points, drawn from my study, serve as a basis for identifying a product-service system design as future work:

- Products have been shown to have potential to create new opportunities for mothers with SCI to improve meaningful mothering experiences.
- The mothers with SCI in this study preferred to use a product instead of relying on a third party.
- All the mothers in this study reported a lack of availability of appropriate child-caring products in Aotearoa New Zealand that met their needs.

- Several mothers applied creative solutions to modify existing products to address their needs.
- The few readily available 'fit' products are often expensive.
- Child-caring products are mostly used for less than three years.
- Several mothers showed their interest in hiring instead of purchasing products.

The idea of the product-service system is aligned customisation in product design. Moreover, new manufacturing methods and technologies such as 3D printing would assist manufacturers to develop 'fit' products more affordably. Product-service system design would not only consider the economic approach of customised products but it would also add sustainable value to the life cycle of a product. Consequently, the life cycle of a product could be extended by reusing products.

Such a product-service system could facilitate the increased availability of products for parents with SCI by bypassing individual ownership of products and creating a more socially equitable solution. Consequently, such a service could shifting from designing and manufacturing products, to a system of products and services that are jointly capable of fulfilling the needs of parents with SCI by customising, reusing and sharing products.

A third direction for future research could be to explore the role of products to construct meaningful experiences for fathers with SCI and for people with conditions that might impair their everyday activities, for example, muscular dystrophy or rheumatoid arthritis or those with hearing or vision impairments. Similarly, co-design could be used to assist in the development of products used by people living with chronic medical conditions, such as Chronic Obstructive Pulmonary Disease. Such research ideally should include participants from diverse cultures who may have different

views regarding both the reliance on a third party and using products. This would allow researchers to paint a more comprehensive and contextually nuanced picture of the role of products in constructing meaningful experiences for disabled people. Ideally, such explorations would lead to designing 'fit' products that better meet the needs of disabled people. However, each project would need to take into account the different abilities and cultural values so that the design processes were accessible and appropriate.

9.5 Conclusion

In this chapter, I discussed the research findings by linking the theoretical arguments that were described in Chapter 3. The application of feminist disability theory through iterative co-design processes helped me to better understand the impact of the social construction of an 'able-bodied' mother on the construction of meaningful mothering experiences with SCI.

The findings of research cycles highlighted the importance of giving a voice to marginalised users to better understand their unmet needs through the design process. Furthermore, findings revealed how essentialist standards of product design can lead to the marginalisation of the mothers who do not meet these standards.

According to findings, the impact of the social construction of an 'able-bodied' mother and product design based on dominant able-bodied users led the mothers to fit themselves to the misfit social and material environment. My findings suggest that design based on body variations instead of applying essentialist standards could lead to designing a material environment that is usable, desirable and meaningful for all of us including the mothers with SCI. It is hoped that this research has promoted a deeper understanding of how the misfit interaction between bodies and material environment can impact on the construction of meaningful mothering experiences with SCI.

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Appendices

Appendix A₁: Ethics approval

AUTEC Secretariat

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29 March 2018

Debbie Payne
Faculty of Health and Environmental Sciences

Dear Debbie

Re Ethics Application: **18/72 Towards an exploration of the interplay between mothers with spinal cord injury and child-caring products**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 28 March 2021.

Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/researchethics.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/researchethics.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: http://www.aut.ac.nz/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: n.tolooei@gmail.com; Stephen Reay

Appendix A₂: Ethics approval (Cycle II)
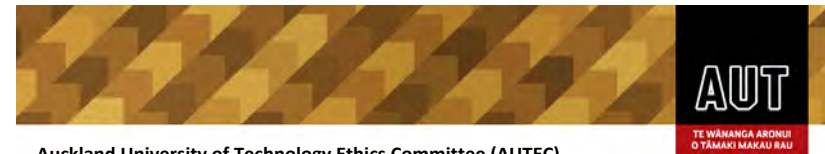
Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

30 August 2018

Debbie Payne
Faculty of Health and Environmental Sciences

Dear Debbie

Re: Ethics Application: **18/72 Towards an exploration of the interplay between mothers with spinal cord injury and child-caring products**

Thank you for your request for approval of amendments to your ethics application.

The application for the second stage of the research for the individual co-design session is approved.

Non-Standard Conditions of Approval

1. Approval for the 3rd stage is pending

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by AUTEC before commencing your study.

I remind you of the **Standard Conditions of Approval**.

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/research/researchethics.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/research/researchethics.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: http://www.aut.ac.nz/research/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. If the research is undertaken outside New Zealand, you need to meet all locality legal and ethical obligations and requirements.

For any enquiries please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: n.tolooei@gmail.com; Stephen Reay

Appendix A₃: Ethics Approval (Cycle III)
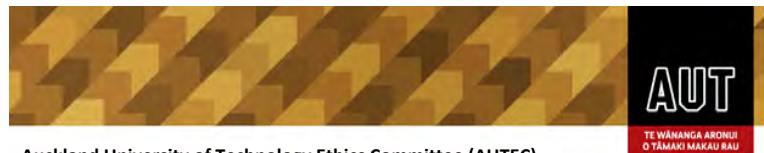
Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

13 November 2019

Debbie Payne
Faculty of Health and Environmental Sciences

Dear Debbie

Re: Ethics Application: **18/72 Towards an exploration of the interplay between mothers with spinal cord injury and child-caring products**

Thank you for your request for approval of amendments to your ethics application.

The amendment to allow additional stage of research, participant feedback is approved

I remind you of the **Standard Conditions of Approval**.

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: n.tolooei@gmail.com; Stephen Reay

Appendix A₄: Ethics Approval (Cycle IV)

Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

14 February 2020

Debbie Payne
Faculty of Health and Environmental Sciences

Dear Debbie

Re: Ethics Application: **18/72 Towards an exploration of the interplay between mothers with spinal cord injury and child-caring products**

Thank you for your request for approval of an amendment to your ethics application.

The amendment to the data collection protocol from focus groups to individual interview is approved.

Non-Standard Conditions of Approval

1. Please update the name of the Executive Secretary to Carina Meares.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by AUTEC before commencing your study.

I remind you of the **Standard Conditions of Approval**.

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

Yours sincerely,

Carina Meares
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: n.tolooei@gmail.com; Stephen Reay

Appendix B₁: Participants Information Sheet (Cycle I)

AUT
TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

Participant Information Sheet

Date Information Sheet Produced:

28/ 03/ 2018

Project Title

Towards an Exploration of the Interplay between Mothers with Spinal Cord Injury (SCI) and Child-caring Products

An Invitation

Hello and Kia ora,

My name is Nata Tolooei. I am a PhD student at Auckland University of Technology (AUT). I have been a product designer for over 8 years. I have also undertaken a range of design projects for people living with disability. In this study, I would like to explore if there are devices or products that might be useful to mothers who have experienced a spinal cord injury.

Studies show that disabled mothers have unmet needs and that the lack of appropriate equipment or products creates barriers to their ability to carry out tasks or activities associated with parenting. An earlier study in New Zealand identified that there is a need to address the physical needs of disabled mothers; for instance, adaptive equipment for changing nappies, lifting, breastfeeding and bathing. My search of the literature has also shown that there has been little consultation with disabled mothers in the design process of products to find out what their needs are.

This research is being undertaken as a part of my PhD degree at the School of Clinical Sciences, AUT. My focus will be on exploring the interplay between mothers with spinal cord injury and child-caring products. The study has three stages in which I will work with mothers who have experienced a spinal cord injury to develop the prototype model of a child-care product. With your permission, the study and its findings will also be used for academic publications and conference papers. At no time will you or any personal information be in these.

In this first stage I would like to interview up to seven mothers who are:

Either tetraplegic or paraplegic, **and**
Have children aged between 0 – 16 years, **and**
Aged between 20 – 52 years, **and**
Willing to explore their experiences and challenges of mothering and of using child-care products.
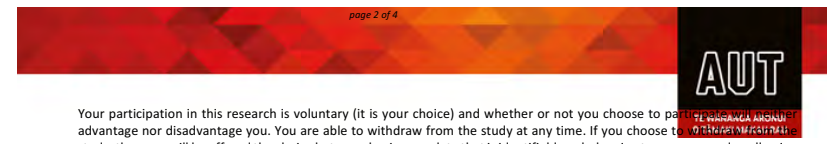
What is the purpose of this research?

In this research, I intend to talk and work with mothers who live with a spinal cord injury to find out what products might facilitate their role as mothers.

How was I identified and why am I being invited to participate in this research?

I have approached my personal networks as well as disability organisations to pass this invitation on to women who have experienced a spinal cord injury, are tetraplegic or paraplegic and who have children aged between 0 to 5 years old.
They have identified you and have emailed or given you have this Information Sheet. If you are interested in finding out more about the study and/or taking part please contact me, my details are below.

How do I agree to take part in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

If you are not able to use a Consent Form, I will record your consent verbally at the beginning of the interview. I will read out the Consent Form and at each bullet point I will ask if you agree to it. This form of Consent will be audio-recorded and then transcribed. You will receive a copy of this.

What will happen in this research?

If you agree to take part in this first stage of my study, this will involve me interviewing you face to face. You could either meet me at AUT's City or North campuses, or we can meet at a place that is most convenient for you. The interview will take about 60 minutes of your time.

Before the interview begins, I will check to ask if you need any further information about the study. I will also ask you to sign a Consent Form. In the interview, I will ask you about your experiences of mothering and about childcare equipment and/or products.

With your permission, I will audio-record our conversation. This will later be transcribed by a professional transcriber or by me. If I use a transcriber s/he will be required to sign a Confidentiality Form. If you wish, I will send you a copy of the interview.

At the end of the interview I will ask you if you would be interested in receiving information about the two other stages of this research project.

What are the discomforts and risks?

You might feel uncomfortable sharing your personal experiences and being recorded during your interview. I would like to point out that this research project focuses on the patterns and trends that emerge from the interviews rather than making any personal judgements. The recordings will be used only for the purpose of this research.

How will these discomforts and risks be alleviated?

To maintain your confidentiality, there will be no mentioning of your name, or of any personal information. In this first stage only I will know who has taken part in my study.

AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research, and are not for other general counselling needs. To access these services, you will need to:

- drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992

- let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

You can find out more information about AUT counsellors and counselling on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

What are the benefits?

It is hoped that parents who live with a spinal cord injury, health professionals, and product designers may benefit from this research. Furthermore, the completion of the study will benefit me to obtain my PhD degree. I also anticipate that the research findings of the study will contribute to theory development and the improvement of empirical knowledge by shedding light on how mothers with spinal cord injury interact with child-caring products. It may be that I find new design solutions. The design outcome created from this research will remain the intellectual property of the researcher. However, all participants and contributors will be acknowledged for their role in the research and referenced

accordingly within the publications produced as an output of this research. In the acknowledgment, the pa[...]
be referenced as participants. Thus, participants' names will be kept confidential. It is important to note, [...]
the outcome of the research might not lead to a specific physical product.

How will my privacy be protected?

Your privacy will be protected by me not me using your name in the research. At the beginning of the interview, I will ask you to give me a pseudonym, that is, another name, not your own, that you will be known by for this research. Any personal information that could identify you will be removed from the interview transcript. The transcriptionist will sign a Confidentiality Agreement.

The interview will take place at a location that is most convenient for you.

All the data collected from you will be kept on a computer that is password protected and the transcriptions as a hard copy will be in a locked cabinet in my primary supervisor's office. The completed Consent Forms will be stored separately from the anonymous data. The anonymous data will be stored for six years and will then be destroyed.

What are the costs of participating in this research?

The research will involve your time. For this first cycle this will be approximately an hour of your time. As a small gesture of thanks for taking part you will receive a $20 grocery voucher.
If you are thinking about taking part in the other two stages of this research, I've given an outline below, but your participation in these will confirmed the end of Stage One.

Second Stage: Individual Collaborative Design Session
This stage intends to explore how to facilitate mothering with spinal cord injury through collaborative design session. At this stage, you will share your experiences and ideas to find new ideas for mothering activities. This codesign session will focus on a specific activity (for instance bathing, lifting or feeding a child). The codesign session will consist of one on one interview, audio recording and observation.
We will use drawing maps, diagram, flowcharts and making 3D objects with clay to explore the current challenges. Thus, this session will be used to find out new opportunities and ideas for child-caring products which facilitate mothering activities.
This stage will take about 60 minutes of your time and will take place in a location of your choice (e.g. their home, office, etc.) for your comfort.

Third Stage: Group Collaborative Design Session
This stage is the same as the second stage but it will be done in the group and in two parts. You will make prototypes in a group with up to seven mothers who have also experienced a spinal cord injury.
In this first part, the group will decide which of the ideas will be developed into a prototype (physical final version of the product). This will take approximately one hour and will involve travel to a location that is convenient for you all and is wheelchair accessible.

In the second part, I will produce the prototype in 3D design software. I will also add details regarding technical issues, material and manufacture. Then, in a second focus group with the mothers I will present the prototype to obtain your feedback. This will take approximately one hour and will involve travel to a location that is convenient for you all and is wheelchair accessible.

What opportunity do I have to consider this invitation?

Please let me know if you are willing to participate in this first stage of the research project within two weeks of receiving the invitation. Do not hesitate to contact me via email or phone if you need any more information to help you decide whether or not you wold like to take part.

How do I agree to participate in this research?

After I will give you a hard copy of a Consent Form prior to the interview.

Will I receive feedback on the results of this research?

Yes, a summary of the research findings will be given to all participants who indicate their interest on the Consent Form.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, A/Prof. Deborah Payne, dpayne@aut.ac.nz, +64 9 921 9999 ext 7112

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext. 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

RESEARCHER CONTACT DETAILS:
Nata Tolooei
n.tolooei@gmail.com

PROJECT SUPERVISOR CONTACT DETAILS:
A/Prof. Deborah Payne,
Faculty of Health and Environment Sciences
AUT University
Phone: +64 9 921 9999 ext 7112
Email: dpayne@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on *type the date final ethics approval was granted*, **AUTEC Reference number** *type the reference number*.

Appendix B₂: Participants Information Sheet (Cycle II)

Appendix A- Participant Information Sheet

Date Information Sheet Produced:

30. 08. 2018

Project Title

Towards an Exploration of the Interplay between Mothers with Spinal Cord Injury (SCI) and Child-caring Products

An Invitation

Hello and Kia ora,

My name is Nata Tolooei. I am a PhD student at Auckland University of Technology (AUT). I have been a product designer for over 8 years. I have also undertaken a range of design projects for people living with disability. In this study, I would like to explore if there are devices or products that might be useful to mothers who have experienced a spinal cord injury.

Studies show that disabled mothers have unmet needs and that the lack of appropriate equipment or products creates barriers to their ability to carry out tasks or activities associated with parenting. An earlier study in New Zealand identified that there is a need to address the physical needs of disabled mothers; for instance, adaptive equipment for changing nappies, lifting, breastfeeding and bathing. My search of the literature has also shown that there has been little consultation with disabled mothers in the design process of products to find out what their needs are.

This research is being undertaken as a part of my PhD degree at the School of Clinical Sciences, AUT. My focus will be on exploring the interplay between mothers with spinal cord injury and child-caring products. The study has three stages in which I will work with mothers who have experienced a spinal cord injury to develop the prototype model of a product to facilitate mothering with spinal cord injury. With your permission, the study and its findings will also be used for academic publications and conference papers. At no time will you or any personal information be in these.

This information participant sheet is for the second stage of the research. In the second stage, I would like to have individual co-design sessions with up to seven mothers who are:

Either tetraplegic or paraplegic, **and**

Have children aged between 0 – 16 years, **and**

Aged between 20 – 52 years, **and**

Willing to explore their experiences and challenges of mothering and of using child-care products.

What is the purpose of this research?

In this research, I intend to talk and work with mothers who live with a spinal cord injury to find out what products might facilitate their role as mothers.

How was I identified and why am I being invited to participate in this research?

You participated in the first cycle of my research and indicated at that time that you were interested in taking part in the next cycle. If you are still interested in finding out more about the study and/or taking part please contact me, my details are below.

How do I agree to take part in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

This stage builds on the first and further explores mothering with a spinal cord injury. If you agree to take part in the second stage of my study, we will have an individual co-design session. In the co-design session, we will talk about your experience of mothering with spinal cord injury. Thus, we will have some activities such as sorting pictures and cards, post it notes, drawings, making objects (with materials such as cardboard, cloth or paper), and enacting scenarios. These activities will be done based on your choice and interest. You could either meet me at AUT's City or North campuses, or we can meet at a place that is most convenient for you. The co-design session will take about 60 minutes of your time.

Before the co-design session begins, I will check to ask if you need any further information about the study. I will also ask you to sign a Consent Form. In the co-design session, I will ask you about your experiences of mothering and about childcare equipment and/or products.

With your permission, I will audio-record our conversation. This will later be transcribed by a professional transcriber or by me. If I use a transcriber s/he will be required to sign a Confidentiality Form. If you wish, I will send you a copy of the conversation.

Also with your permission, I would like to photograph and video-record the activities in the co-design session. I will use the video recordings and photos of the session, either complete or in part, alone or in conjunction with any wording and/or drawings solely and exclusively for solely the research's purposes. Your face and identity will not be published and identified. Only my two supervisors and I will view the video. The photos, video and transcripts will be stored on a password protected computer and will be deleted six years after the study's completion.

At the end of the interview I will ask you if you would be interested in receiving information about the next stage of this research project.

What are the discomforts and risks?

You might feel uncomfortable sharing your personal experiences and being recorded during the session. I would like to point out that this research project focuses on the patterns and trends that emerge from the co-design session rather than making any personal judgements. The recordings will be used only for the purpose of this research.

How will these discomforts and risks be alleviated?

To maintain your confidentiality, there will be no mentioning of your name, or of any personal information. In every stage of this study only I will know who has taken part in my study.

Should this study cause you emotional stress, the AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research, and are not for other general counselling needs. To access these services, you will need to:

- You can drop into one of AUT's centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992.
- Let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

You can find out more information about AUT counsellors and counselling on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

What are the benefits?

It is hoped that parents who live with a spinal cord injury, health professionals, and product designers may benefit from this research. Furthermore, the completion of the study will benefit me to obtain my PhD degree. I also anticipate that the research findings of the study will contribute to theory development and the improvement of empirical knowledge by shedding light on how mothers with spinal cord injury interact with child-caring products. It may be that I find new design solutions. The design outcome created from this research will remain the intellectual property of the researcher. It is important to note, however, that the outcome of the research might not lead to a specific physical product.

How will my privacy be protected?

Your privacy will be protected by me and I will not use your name in the research. At the beginning of the co-design session, I will ask you to give me a pseudonym, that is, another name, not your own, that you will be known by for this research. Any personal information that could identify you will be removed from the transcript. The transcriptionist will sign a Confidentiality Agreement.

The co-design session will take place at a location that is most convenient for you.

All the data collected from you will be kept on a computer that is password protected and the transcriptions as a hard copy will be in a locked cabinet in my primary supervisor's office. The completed Consent Forms will be stored separately from the anonymous data in a locked filing cabinet. The anonymous data will be stored for six years and will then be destroyed. Consent forms and transcripts will be stored separately. Data will be stored on a password protected computer. Hard copies of the Consent Forms will be kept in a locked cabinet in the primary supervisor's office.

What are the costs of participating in this research?

The research will involve your time. This will be approximately an hour of your time. As a small gesture of thanks for taking part, you will receive a $20 grocery voucher.

If you are thinking about taking part in the third stage of this research, I've given an outline below, but your participation in this will confirmed the end of Stage Two.

Third Stage: Group Collaborative Design Session

This stage is the same as the second stage but it will be done in the focus group. You will make objects in a group with up to seven mothers who have also experienced a spinal cord injury. This will take approximately one hour and will involve travel to a location that is convenient for you all and is wheelchair accessible.

What opportunity do I have to consider this invitation?

Please let me know if you are willing to participate in this individual co-design session within two weeks of receiving the invitation. Do not hesitate to contact me via email or phone if you need any more information to help you decide whether or not you would like to take part.

How do I agree to participate in this research?

I will give you a hard copy of a Consent Form prior to the codesign session.

Will I receive feedback on the results of this research?

Yes, a summary of the research findings will be given to all participants who indicate their interest on the Consent Form.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, A/Prof. Deborah Payne, dpayne@aut.ac.nz, +64 9 921 9999 ext 7112

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext. 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

RESEARCHER CONTACT DETAILS:

Nata Tolooei
n.tolooei@gmail.com

PROJECT SUPERVISOR CONTACT DETAILS:

A/Prof. Deborah Payne,

Faculty of Health and Environment Sciences
AUT University
Phone: +64 9 921 9999 ext 7112

Email: dpayne@aut.ac.nz

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Approved by the Auckland University of Technology Ethics Committee on *30.08.2018*, AUTEC Reference number *18/72*.

Approved by the Auckland University of Technology Ethics Committee on *30.08.2018*, AUTEC Reference number *18/72*.

280

Appendix B₃: Participants Information Sheet (Cycle III)

Appendix A- Participant Information Sheet

Date Information Sheet Produced:

04 April 2019

Project Title

Towards an Exploration of the Interplay between Mothers with Spinal Cord Injury (SCI) and Child-caring Products

An Invitation

Hello and Kia ora,

My name is Nata Tolooei. I am a PhD student at Auckland University of Technology (AUT). I have been a product designer for over 8 years. I have also undertaken a range of design projects for people living with disability. In the 3ʳᵈ cycle of this study, I would like to explore the devices or products that might be useful to mothers who have experienced a spinal cord injury.

Studies show that disabled mothers have unmet needs and that the lack of appropriate equipment or products creates barriers to their ability to carry out tasks or activities associated with parenting. An earlier study in New Zealand identified that there is a need to address the physical needs of disabled mothers; for instance, adaptive equipment for changing nappies, lifting, breastfeeding and bathing. My search of the literature has also shown that there has been little consultation with disabled mothers in the design process of products to find out what their needs are.

This research is being undertaken as a part of my PhD degree at the School of Clinical Sciences, AUT. My focus will be on exploring the interplay between mothers with spinal cord injury and child-caring products. The study has three stages in which I will work with mothers who have experienced a spinal cord injury to develop the prototype model of a product to facilitate mothering with spinal cord injury. With your permission, the study and its findings will also be used for academic publications and conference papers. At no time will you or any personal information be in these.

I am inviting you to take part in the third cycle of my study as you have taken part in the first two cycles of my project and indicated an interest in taking part in this third cycle. This information participant sheet is for the third cycle of the research. In this workshop I would like to have co-design session with up to five mothers who are:

Either tetraplegic or paraplegic, **and**

Have children aged between 0 – 16 years, **and**

Aged between 20 – 52 years, **and**

Willing to explore their experiences and challenges of mothering and of using child-care products.

What is the purpose of this research?

In this third cycle of my research, I intend to build on the findings of cycles one and two and further talk and work with mothers who live with a spinal cord injury to develop ideas of what products might facilitate their role as mothers.

How was I identified and why am I being invited to participate in this research?

You participated in the second stage of my research and indicated at that time that you were interested in taking part in the next cycle. If you are still interested in finding out more about the study and/or taking part please contact me, my details are below.

How do I agree to take part in this research?

Your participation in the last cycle of this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

This stage builds on the second stage and further explores mothering with a spinal cord injury. If you agree to take part in the third cycle of my study, we will have a co-design session. This session is a group session with four other women who have also taken part in cycles one and two.

In the co-design session, I will share my findings about the experiences of mothering and the childcare equipment and/or products that have been identified in the previous cycle. We will talk discuss these and then have some activities such as sorting pictures and cards, post it notes, drawings, making objects (with materials such as cardboard, cloth or paper), and enacting scenarios. These activities will be done based on the group's choice and interest. The co-design session will take about two hours of your time. The workshop will be held at Yes Disability Centre, in North Shore with accessible amenities.

Before the co-design session begins, I will check to ask if you need any further information about the study. I will also ask you to sign a Consent Form.

With your permission, I will audio-record our conversation. This will later be transcribed by a professional transcriber or by me. If I use a transcriber s/he will be required to sign a Confidentiality Form. If you wish, I will send you a copy of the workshop conversation.

Also with your permission, I would like to photograph and video-record the activities in the co-design session. I will use the video recordings and photos of the session, either complete or in part, alone or in conjunction with any wording and/or drawings solely and exclusively for solely the research's purposes. Your face and identity will not be published and identified. Only my two supervisors and I will view the video. The photos, video and transcripts will be stored on a password protected computer and will be deleted six years after the study's completion.

What are the discomforts and risks?

You might feel uncomfortable sharing your personal experiences and being recorded during the session. I would like to point out that this research project focuses on the patterns and trends that emerge from the co-design session rather than making any personal judgements. The recordings will be used only for the purpose of this research.

A further risk of taking part in this codesign session is that you will be known to the other women.

How will these discomforts and risks be alleviated?

To maintain your confidentiality, there will be no mentioning of your name, or of any personal information in the transcripts. At the codesign session you can choose what and how much information you want to share about yourself with the other women. At the beginning of the workshop we will establish ground rules where you and the other women can identify the processes that we follow to ensure that you feel comfortable and safe about taking part. These will include that no information about the working group will be shared with others outside of the group.

Should this study cause you emotional stress, the AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only

available for issues that have arisen directly as a result of participation in the research, and are not for other general counselling needs. To access these services, you will need to:

- You can drop into one of AUT's centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992.

- Let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

You can find out more information about AUT counsellors and counselling on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

What are the benefits?

In relation to this codesign session, it may be that you enjoy meeting other mothers who live with a spinal cord injury.

In relation to the study overall, it is hoped that parents who live with a spinal cord injury, health professionals, and product designers may benefit from this research. Furthermore, the completion of the study will benefit me to obtain my PhD degree. I also anticipate that the research findings of the study will contribute to theory development and the improvement of empirical knowledge by shedding light on how mothers with spinal cord injury interact with child-caring products. It may be that I find new design solutions. The design outcome created from this research will remain the intellectual property of the researcher. It is important to note, however, that the outcome of the research might not lead to a specific physical product.

How will my privacy be protected?

Your privacy will be protected by me and I will not use your name in the research. At the beginning of the co-design session, I will ask you to give me a pseudonym, that is, another name, not your own, that you will be known by for this research. Any personal information that could identify you will be removed from the transcript. The transcriptionist will sign a Confidentiality Agreement. As above we will set the ground rule that no information about the working group will be shared with others outside of the group

All the data collected from you will be kept on a computer that is password protected and the transcriptions as a hard copy will be in a locked cabinet in my primary supervisor's office. The completed Consent Forms will be stored separately from the anonymous data in a locked filing cabinet. The anonymous data will be stored for six years and will then be destroyed. Consent forms and transcripts will be stored separately. Data will be stored on a password protected computer. Hard copies of the Consent Forms will be kept in a locked cabinet in the primary supervisor's office.

What are the costs of participating in this research?

The research will involve your time. This will be approximately two hours of your time plus travel to the North Shore. As a small gesture of thanks for taking part, you will receive a $20 grocery voucher.

What opportunity do I have to consider this invitation?

Please let me know if you are willing to participate in this co-design session within two weeks of receiving the invitation. Do not hesitate to contact me via email or phone if you need any more information to help you decide whether or not you would like to take part.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, A/Prof. Deborah Payne, dpayne@aut.ac.nz, +64 9 921 9999 ext 7112

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext. 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

RESEARCHER CONTACT DETAILS:

Nata Tolooei
n.tolooei@gmail.com

PROJECT SUPERVISOR CONTACT DETAILS:

A/Prof. Deborah Payne,

Faculty of Health and Environment Sciences
AUT University
Phone: +64 9 921 9999 ext 7112

Email: dpayne@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on *type the date final ethics approval was granted*, **AUTEC Reference number** *type the reference number*.

Appendix B₄: Information Participants Sheet (Cycle IV)

Participant Information Sheet

Date Information Sheet Produced:

Project Title

Towards an Exploration of the Interplay between Mothers with Spinal Cord Injury (SCI) and Childcaring Products

An Invitation

Hello and Kia ora,

My name is Nata Tolooei. I am a PhD student at Auckland University of Technology (AUT). I have been a product designer for over 8 years. I have also undertaken a range of design projects for people living with disability. In the final stage of this study, I would like to share my final design with you and hear you feedback.

Studies show that disabled mothers have unmet needs and that the lack of appropriate equipment or products creates barriers to their ability to carry out tasks or activities associated with parenting. An earlier study in New Zealand identified that there is a need to address the physical needs of disabled mothers; for instance, adaptive equipment for changing nappies, lifting, breastfeeding and bathing. My search of the literature has also shown that there has been little consultation with disabled mothers in the design process of products to find out what their needs are.

This research is being undertaken as a part of my PhD degree at the School of Clinical Sciences, AUT. My focus will be on exploring the interplay between mothers with spinal cord injury and child-caring products. With your permission, the study and its findings will be used for academic publications and conference papers. At no time will you or any personal information be in these.

I am inviting you to take part in the final stage of my study as you have taken part in the previous cycles of my project and indicated an interest in taking part in this stage. This information participant sheet is for the final stage of the research. In this workshop I would like to have co-design session with up to five mothers who are:

Either tetraplegic or paraplegic, **and**

Have children aged between 0 – 16 years, **and**

Aged between 20 – 52 years, **and**

Willing to explore their experiences and challenges of mothering and of using child-care products.

What is the purpose of this research?

In this stage of my research, I intend to share my final design and further talk and work with mothers who live with a spinal cord injury to hear their feedback on the final design and codesign process.

How was I identified and why am I being invited to participate in this research?

You participated in the previous stages of my research and indicated at that time that you were interested in taking part in the next stage. If you are still interested in finding out more about the study and/or taking part please contact me, my details are below.

How do I agree to take part in this research?

Your participation in the final stage of this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

This stage builds on the third stage and I intend to hear your feedback about my final design and codesign process. If you agree to take part in this stage of my study, we will have a group session. This session is a group session with four other women who have also taken part in cycles one, two and three.

In the session, I will share my findings about the experiences of mothering and the childcare equipment and/or products that have been identified in the previous cycle. We will talk discuss these and then have some activities such as sorting pictures and cards, post it notes, drawings, making objects (with materials such as cardboard, cloth or paper), and enacting scenarios. These activities will be done based on the group's choice and interest. The co-design session will take about one hour of your time. The workshop will be held at Yes Disability Centre, in North Shore with accessible amenities.

Before the co-design session begins, I will check to ask if you need any further information about the study. I will also ask you to sign a Consent Form.

With your permission, I will audio-record our conversation. This will later be transcribed by a professional transcriber or by me. If I use a transcriber s/he will be required to sign a Confidentiality Form. If you wish, I will send you a copy of the workshop conversation.

Also with your permission, I would like to photograph and video-record the activities in the co-design session. I will use the video recordings and photos of the session, either complete or in part, alone or in conjunction with any wording and/or drawings solely and exclusively for solely the research's purposes. Your face and identity will not be published and identified. Only my two supervisors and I will view the video. The photos, video and transcripts will be stored on a password protected computer and will be deleted six years after the study's completion.

What are the discomforts and risks?

You might feel uncomfortable sharing your personal experiences and being recorded during the session. I would like to point out that this research project focuses on the patterns and trends that

emerge from the co-design session rather than making any personal judgements. The recordings will be used only for the purpose of this research.

A further risk of taking part in this codesign session is that you will be known to the other women.

How will these discomforts and risks be alleviated?

To maintain your confidentiality, there will be no mentioning of your name, or of any personal information in the transcripts. At the codesign session you can choose what and how much information you want to share about yourself with the other women. At the beginning of the workshop we will establish ground rules where you and the other women can identify the processes that we follow to ensure that you feel comfortable and safe about taking part. These will include that no information about the working group will be shared with others outside of the group.

Should this study cause you emotional stress, the AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research, and are not for other general counselling needs. To access these services, you will need to:

- You can drop into one of AUT's centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992.

- Let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

You can find out more information about AUT counsellors and counselling on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-andwellbeing/counselling.

What are the benefits?

In relation to this codesign session, it may be that you enjoy meeting other mothers who live with a spinal cord injury.

In relation to the study overall, it is hoped that parents who live with a spinal cord injury, health professionals, and product designers may benefit from this research. Furthermore, the completion of the study will benefit me to obtain my PhD degree. I also anticipate that the research findings of the study will contribute to theory development and the improvement of empirical knowledge by shedding light on how mothers with spinal cord injury interact with child-caring products. It may be that I find new design solutions. The design outcome created from this research will remain the intellectual property of the researcher. It is important to note, however, that the outcome of the research might not lead to a specific physical product.

How will my privacy be protected?

Your privacy will be protected by me and I will not use your name in the research. At the beginning of the co-design session, I will ask you to give me a pseudonym, that is, another name, not your own, that you will be known by for this research. Any personal information

that could identify you will be removed from the transcript. The transcriptionist will sign a Confidentiality Agreement. As above we will set the ground rule that no information about the working group will be shared with others outside of the group

All the data collected from you will be kept on a computer that is password protected and the transcriptions as a hard copy will be in a locked cabinet in my primary supervisor's office. The completed Consent Forms will be stored separately from the anonymous data in a locked filing cabinet. The anonymous data will be stored for six years and will then be destroyed. Consent forms and transcripts will be stored separately. Data will be stored on a password protected computer. Hard copies of the Consent Forms will be kept in a locked cabinet in the primary supervisor's office.

What are the costs of participating in this research?

The research will involve your time. This will be approximately two hours of your time plus travel to the North Shore. As a small gesture of thanks for taking part, you will receive a $20 grocery voucher.

What opportunity do I have to consider this invitation?

Please let me know if you are willing to participate in this co-design session within two weeks of receiving the invitation. Do not hesitate to contact me via email or phone if you need any more information to help you decide whether or not you would like to take part.

How do I agree to participate in this research?

I will give you a hard copy of a Consent Form prior to the codesign session.

Will I receive feedback on the results of this research?

Yes, a summary of the research findings will be given to all participants who indicate their interest on the Consent Form.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, A/Prof. Deborah Payne, dpayne@aut.ac.nz, +64 9 921 9999 ext 7112

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext. 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

RESEARCHER CONTACT DETAILS:
Nata Tolooei
n.tolooei@gmail.com

Appendix C₁: Consent Form (Cycle I)

Consent Form

Project title: **Towards an Exploration of the Interplay Between Mothers with SCI and Child-caring Products**

Project Supervisor: **A/ Prof. Deborah Payne**
Researcher: **Nata Tolooei**

○ I have read and understood the information provided about this research project in the Information Sheet dated ………………………..

○ I have had an opportunity to ask questions and to have them answered.

○ I understand that notes will be taken during the interview and that they will also be audio-taped and transcribed.

○ I understand that I may withdraw from the study at any time during the interview.

○ If I withdraw prior to the commencement of data analysis, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

○ I agree to take part in this research.

○ The design outcome created from this research will remain the intellectual property of the researcher.

○ I wish to receive a copy of the report from the research (please tick one):   Yes ○   No ○

○ If you are interested, this study will involve two further stages in which the researcher, Nata, will work with mothers who live with a spinal cord injury to develop a prototype of a product that may assist in child caring.

   I am interested in receiving information about taking part in the two collaborative design sessions:
   Yes ○   No ○

Participant's signature:..

Participant's name: ....
Participant's Contact Details (if appropriate):
…………………………………………………………………………..
…………………………………………………………………………..
…………………………………………………………………………..
…………………………………………………………………………..
Date:

Approved by the Auckland University of Technology Ethics Committee on type the date on which the final approval was granted AUTEC Reference number type the AUTEC reference number
Note: The Participant should retain a copy of this form.

Appendix C₂: Consent Form (Cycle II)
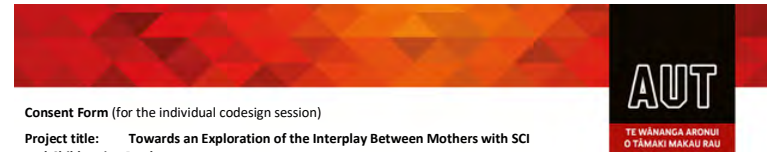
Consent Form (for the individual codesign session)

Project title: **Towards an Exploration of the Interplay Between Mothers with SCI and Child-caring Products**

Project Supervisor: A/ Prof. Deborah Payne

Researcher: Nata Tolooei

I have read and understood the information provided about this research project in the Information Sheet dated ………………………..

○ I agree to take part in this research.
○ I have had an opportunity to ask questions and to have them answered.
○ I understand that notes will be taken during the co-design session. The co-design session will also be audio-taped and transcribed.
○ I permit the researcher to use the co-design video recordings and photos that are part of this project, either complete or in part, alone or in conjunction with any wording and/or drawings solely and exclusively for solely the purpose of the research's purposes.
○ I understand that the video recordings will be used for academic purposes only and will not be used in any form outside of this project without my written permission.
○ I understand that there will be no reference to my name and/or identity in the research project.
○ I understand that I may withdraw from the study at any time during the codesign sessions.
○ If I withdraw prior to the commencement of data analysis, I understand that all relevant information including transcripts and photos will be destroyed.
○ The design outcome created from this research will remain the intellectual property of the researcher.

○ I wish to receive a copy of the report from the research (please tick one): Yes○ No○

Cycle 3

   If you are interested, this study will involve another stage that the researcher, Nata, will work with mothers who live with a spinal cord injury to develop a prototype of a product that may assist in child caring.

○ I am interested in receiving information about taking part in the next collaborative design sessions: Yes○   No○

Participant's signature:
...

Participant's name:
....

Participant's Contact Details (if appropriate):

....

Date

Approved by the Auckland University of Technology Ethics Committee on 30.08.2018, AUTEC Reference number 18/72.

Appendix C₃: Consent Form (Cycle III)

Appendix C- Consent Form (for Codesign Session)

Project title: Towards an Exploration of the Interplay Between Mothers with SCI and Child-caring Products

Project Supervisor: A/ Prof. Deborah Payne

Researcher: Nata Tolooei

I have read and understood the information provided about this research project in the Information Sheet dated ………………………

○ I agree to take part in this research.
○ I have had an opportunity to ask questions and to have them answered.
○ I understand that notes will be taken during the co-design session. The co-design session will also be audio-taped and transcribed.
○ I permit the researcher to use the co-design video recordings and photos that are part of this project, either complete or in part, alone or in conjunction with any wording and/or drawings solely and exclusively for solely the purpose of the research's purposes.
○ I understand that the video recordings will be used for academic purposes only and will not be used in any form outside of this project without my written permission.
○ I understand that there will be no reference to my name and/or identity in the research project.
○ I understand that I may withdraw from the study at any time during the codesign sessions.
○ If I withdraw prior to the commencement of data analysis, I understand that all relevant information including transcripts and photos will be destroyed.
○ The design outcome created from this research will remain the intellectual property of the researcher.

○ I wish to receive a copy of the report from the research (please tick one):   Yes   No

Participant's signature: ....

Participant's name: ....

Participant's Contact Details (if appropriate):
……
……

Date:

Appendix C₄: Consent Form (Cycle IV)

Appendix C

Project title: Towards an Exploration of the Interplay Between Mothers with SCI and Child-caring Products

Project Supervisor: A/ Prof. Deborah Payne

Researcher: Nata Tolooei

I have read and understood the information provided about this research project in the Information Sheet dated ………………………

○   I agree to take part in this research.
○   I have had an opportunity to ask questions and to have them answered.
○   I understand that notes will be taken during the co-design session. The co-design session will also be audio-taped and transcribed.
○   I permit the researcher to use the co-design video recordings and photos that are part of this project, either complete or in part, alone or in conjunction with any wording and/or drawings solely and exclusively for solely the purpose of the research's purposes.
○   I understand that the video recordings will be used for academic purposes only and will not be used in any form outside of this project without my written permission.
○   I understand that there will be no reference to my name and/or identity in the research project.
○   I understand that I may withdraw from the study at any time during the codesign sessions.
○   If I withdraw prior to the commencement of data analysis, I understand that all relevant information including transcripts and photos will be destroyed.
○   The design outcome created from this research will remain the intellectual property of the researcher.

○   I wish to receive a copy of the report from the research (please tick one): Yes No

Participant's   signature:
    ....

Participant's   name:
    .... Participant's Contact

Details (if appropriate):

…………………………………………………………………………………………
…………………………………………………………………………………………

Date:

Appendix D₁: Topic Guide (Cycle I)

Appendix F- Topic Guides (Cycle I)

Participant's Information:
No. ....
Age ....   The level of SCI ....   Education..................   Occupation ....
Number of Children........   Age of Children ....

Semi structured Topic Guide:

- What does being a "mother" mean to you?
- What do "mothers" do?
- What did you/would you like to do as a mother?
- Describe your experience of mothering? What have you experienced?
- What activities do you like to do as a mother?
- Did you experience any challenges during your motherhood?
- What are the things or situations that influenced this experience?
- How was the experience of mothering with SCI?
- If you have answered "yes", please say which activities were more challenging?
- What was the most challenging things about your mothering? Why?
- At what age (or period) of your child you had the most issues?
- Did you use any child-caring product to facilitate your mothering? Why? How?
- Can you describe your experience with them? How would you describe the interaction process?
- What kinds of products would facilitate you to carry out the activities?
- What kinds of products do you prefer?
- Did you wish to have any child-caring product during mothering?
                 Yes............ No...............
- If you answered question no.12 'yes', please describe the product/s?
- In the next stages of this research, how would you like to work together in codesign sessions?

Do you have any questions?

Thank you for your time and participation!

Appendix D₂: Topic Guide (Cycle II)

Appendix B- Topic Guides (Cycle II)

- What is the notion of being a mother? (Who is a mother)
- What are mothering activities?
- Is the most challenging mothering activity similar to the most significant activity for you?
- What is relation between being a mother and mothering tasks?
- What are the positive things that you bring for your child/ren?
- What are your priorities in mothering activities? Why?
- How much independency is important to you? Why?
- What is your idea about relying on the third party? Why?
- Do you think that the third party would affect the mother-child relationship? How?
- Is bonding important to you?
- Do you prefer to use a product rather than asking help or relying on the third party? Why?
- What are the most important factors (specifications, features) of a product that could facilitate your mothering tasks?

Appendix D₃: Topic Guide (Cycle III)

Appendix B- Indicative Questions for the Co-design Session

Topic Guides

One of the findings of my study was the presence of a third party, that is, a person who cared for your child. I plan to explore this further

- What are your thoughts and views about relying on the third party? Why?
- Who is the third party for you?
- Why do you prefer to use a product instead of relying on a third party?
- How much is independence important to you? Why?
- What are the most important factors (specifications, features) of a product that could facilitate your mothering tasks?

Appendix D₄: Topic Guide (Cycle IV)

Appendix B- Indicative Questions for the Co-design Session

Topic Guides

- Did codesign process assist you to share your mothering experiences? How?
- Did codesign process assist you to express your ideas? How?
- What is your idea about an accessible recliner?
- Do you think an accessible recliner would create new opportunities to engage with your child?

Appendix E: Confidentiality Agreement

Appendix E- Transcriptionist Confidentiality Protocol

Confidentiality Agreement

For someone transcribing data, e.g. audio-tapes of interviews.

Project title: **Towards an Exploration of the Interplay between Mothers with SCI and Child-caring Products**

Project Supervisor: **A/ Prof. Deborah Payne**

Researcher: **Nata Tolooei**

○   I understand that all the material I will be asked to transcribe is confidential.

○   I understand that the contents of the tapes or recordings can only be discussed with the researchers.

○   I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature: ....

Transcriber's name: ....

Transcriber's Contact Details (if appropriate):

....

....

....

....

Date:

Project Supervisor's Contact Details (if appropriate):

....

....

....

....

Approved by the Auckland University of Technology Ethics Committee on *type the date on which the final approval was granted* **AUTEC Reference number** *type the AUTEC reference number*

Note: The Transcriber should retain a copy of this form.

Appendix F: PowerPoint Presentation (Cycle IV)

Towards the Exploration of the Interplay Between Mothers with SCI and Child-caring Products

PhD Candidate: Nata Tolooei
Supervisors: A/Prof. Deborah Payne & Prof. Stephen Reay

February 2020

INTRODUCTION

- This presentation focuses on the findings from three cycles of a PhD research project that uses the integration of feminist disability and codesign to explore mothering experience SCI.

**Cycle I
(Interviews)**

- **Aim:** To explore mother's experiences and challenges

- **Findings:**

  - There was a difference between challenging activities and meaningful experiences.

  - Four mothering activities were chosen for further exploration including:
    - Going to the ground level
    - Bathing a child
    - Wheeling and carrying a child
    - Picking up a child.

  - The most challenging period for mothers was during the first three years of their child's life.

**Cycle II
(Individual Codesign Workshop)**

- **Aim:** To explore meaningful mothering experiences.

- **Findings:**

  - Mothering activity is a love language.

  - An accessible product would create a new opportunity for mothers to bond and engage with a child.

  - Mothers prefer to use a product instead of relying on a third-party in the home environment.

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Cycle III
(Codesign Workshop)

■ **Aim:**

- Exploring the characteristics of an accessible product/furniture.

- Exploring what "home" means to mothers.

■ **Findings:**

- Mothers will not use an accessible product with medical characteristics .

- Furniture and products with medical characteristics make a home an institutionalised place.

- Accessible recliner was one of the most popular ideas.

■ **Cycle IV.** **Your Feedback**

This content has been removed by the author due to copyright issues.

Thank You!