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When I am no longer alive

Parents’ views on the future of their disabled adult children with high and complex needs

Hemant Thakkar

Abstract

Sooner or later, a question that starts concerning most parents of children with high and complex needs is: What will happen to my child when I am no longer alive? The answer to this question depends upon the parents’ perception of how well their children will be supported in the future when they are no longer there to care for, or advocate for, them. The level of formal (publicly funded) support and informal support (provided voluntarily by family, friends and others) that the parents have access to, or can rely upon, plays a vital part in shaping this perception.

In this qualitative study, 14 New Zealand parents and 18 Indian parents were interviewed with a view to understanding their wishes and worries concerning the long-term care and wellbeing of their adult children with high and complex needs; and ascertaining their views on the support mechanisms (both formal and informal) that they consider and value as being useful for their children’s future. Thirteen key informants from both countries were also interviewed with a view to getting an additional perspective on the issues raised by the parents. The data were analysed using a thematic analysis approach guided by a rights-based conceptual framework.

The findings revealed that, due to the failure on the part of the policy makers to understand and appreciate the unique support needs of adults with high and complex needs, the formal support system of both countries are falling short in upholding these adults’ rights to adequate support in living and participating in the community on an equal basis with others. It was also found that this group of people are often deprived of opportunities to exercise choice and control over their lives due to the inability of people from both formal and informal networks to understand their children’s non-verbal communication used to express needs and preferences. This study has highlighted that, to adequately support adults with high and complex needs beyond their parents’ lifetimes, it becomes vital that they are provided funding and services commensurate to their needs; that they receive well-coordinated support from both formal and informal systems; and that their parents’ expertise and knowledge are utilised through a meaningful partnership with the state in designing and implementing future-oriented policies and services.
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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACC</td>
<td>Accident Compensation Commission, New Zealand</td>
</tr>
<tr>
<td>BPL</td>
<td>Below Poverty Line</td>
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<tr>
<td>CBR</td>
<td>Community Based Rehabilitation</td>
</tr>
<tr>
<td>CCL</td>
<td>Choice in Community Living</td>
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<tr>
<td>DDRC</td>
<td>District Disability Rehabilitation Centre</td>
</tr>
<tr>
<td>DEPD</td>
<td>Department of Empowerment of Persons with Disabilities, India</td>
</tr>
<tr>
<td>DPO</td>
<td>Disabled Persons’ Organisation</td>
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<tr>
<td>DRM</td>
<td>Disability Rights Movement</td>
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<tr>
<td>EGL</td>
<td>Enabling Good Lives</td>
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<tr>
<td>HCN</td>
<td>High and Complex Needs</td>
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<tr>
<td>IC</td>
<td>Informed Consent</td>
</tr>
<tr>
<td>LIG</td>
<td>Lower Income Group</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health, New Zealand</td>
</tr>
<tr>
<td>MSD</td>
<td>Ministry of Social Development, New Zealand</td>
</tr>
<tr>
<td>MSJE</td>
<td>Ministry of Social Justice and Empowerment, India</td>
</tr>
<tr>
<td>National Trust Act</td>
<td>The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, India</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Government Organisation</td>
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<tr>
<td>NZDS</td>
<td>New Zealand Disability Strategy</td>
</tr>
<tr>
<td>NZSL</td>
<td>New Zealand Sign Language</td>
</tr>
<tr>
<td>ODI</td>
<td>Office for Disability Issues, New Zealand</td>
</tr>
<tr>
<td>PIS</td>
<td>Participant Information Sheet</td>
</tr>
<tr>
<td>PWD Act</td>
<td>The Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act, 1995, India</td>
</tr>
<tr>
<td>PPPR Act</td>
<td>The Protection of Personal and Property Rights Act 1988, New Zealand</td>
</tr>
<tr>
<td>RCI</td>
<td>Rehabilitation Council of India</td>
</tr>
<tr>
<td>RPWD Act</td>
<td>The Rights of Persons with Disabilities Act, 2016, India</td>
</tr>
<tr>
<td>SIL</td>
<td>Supported Independent Living</td>
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<tr>
<td>UNCRPD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
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Chapter 1. Introduction

What will happen to my child when I am no longer alive? Whilst this question often troubles many parents of disabled children, for a majority of the ageing parents of adult children with high and complex needs (HCN)\(^1\), this is perhaps the most worrisome question as, even within the disability population, people with HCN are considered to be the most vulnerable group. Their increased vulnerability compared to other disability groups could be attributed to the nature of the support they require (including intimate personal care) associated with the deficits in cognitive and communication abilities to speak up and fight for their own rights. Their complete reliance on others for most aspects of their everyday lives also makes them easily exposed to various kinds of abuse and neglect (Milner & Mirfin-Veitch, 2012). Therefore, in most cases, the parents of children\(^2\) with HCN end up assuming multiple roles in their children’s lives including being their carer and/or advocate. However, playing such multiple roles takes its toll on the mental and physical health of the parents (Morgan, 2009). Just managing their everyday lives becomes a juggling act. They are required to spend a significant amount of their time in attending to the needs of their child with HCN and at the same time, they might have other children requiring their attention (Bray, Moss, Forrester, & McConnochie, 2005; Vorhaus, 2014). This leaves them with very little time and energy to do anything for themselves and their life becomes captive around their children.

Further, the literature suggests that, due to the advances in medical science and health care, disabled people, including those who have HCN, are living longer (Chakravarti, 2008; Hewitt-Taylor, 2008; NHS choices, 2012; Royal College of Nursing, 2013; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). Thus, more and more parents of people with HCN, previously preparing themselves to see their children die before them, are now likely to face what Morgan (2009) calls, “that nagging question” (p. 19): What will happen to my child when I am no longer alive? Given the vulnerability of their children as discussed above, for the parents who have looked after their children at home all their lives, facing the prospect of leaving them under someone else’s care, becomes a matter of great concern. Several studies have reported parental concerns

\(^1\) Refer to the key concepts section for the definition of ‘high and complex needs.’
\(^2\) This study concerns adults with high and complex needs aged 18 years or over. The terms ‘child’ or ‘children’ are, however, used when making references to their relationship with their parent/s.
around their children’s long-term wellbeing (Hatton, Akram, Shah, Robertson, & Emerson, 2004; Taggart et al., 2012). The level of concern felt by the individual parents would, however, depend upon their perception of how well their children will be supported in the future when they are no longer there to care or advocate for them. For most parents, irrespective of where they live, the support network that they would rely upon to look after their children when they are no longer alive would comprise both formal support and informal support. However, as explained in the section to follow, the availability of, and access to, both formal and informal support differs for parents living in different parts of the world.

### 1.1 Disability support services context

Over the last five decades, the milestones achieved in the disability sector represent advances in both the theoretical aspects of how disability is understood and its consequent practical implications for how disabled people are supported. Theoretical advances include a move away from a medical model (thinking that viewed disability as a personal problem) to a social model worldview that views disability as a societal problem and focuses on the barriers created by the built environment and attitudes of non-disabled people (Oliver, 1990). More recent works of prominent writers in the field have proposed other models, such as a relational model (Thomas, 2004), or an interactional approach (Shakespeare, 2006) of understanding disability which proposes that disablement is caused by the interaction of intrinsic individual factors such as impairment, and the extrinsic structural factors such as societal barriers. Disability theories have also seen a move away from the deficit focus inherent in the medical model to a strengths based approach and consequently the status of disabled people has also changed from being passive recipients of care to active contributors in design and delivery of services. These changes could be attributed largely to the disability rights movement (DRM) that began in the 1980s with disabled people demanding a greater choice and control over the decisions affecting their lives. The persistent efforts of DRM activists worldwide over the last three decades resulted in international recognition of the fundamental human rights as well as various social, economic and cultural rights of disabled people under the United Nations Convention on the Rights of

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3 Refer to the key concepts section for the definitions of the terms ‘formal support’ and ‘informal support.’
Persons with Disabilities (UNCRPD or the Convention) that came into force in 2007 (UN General Assembly, 2006).⁴

In line with the theoretical advances, the changes at practice and policy level in most Western countries (including New Zealand) included significant investment in disability support services and a gradual shift in the approach to supporting people from an institutional model to “community residential” or “independent living” models (Oliver & Barnes, 2012). Under the independent living models, the funding is often given directly to a disabled person or his or her agent. This method of funding support services is called “direct payments” (Scourfield, 2005) or “individualised funding” (Ministry of Health, 2016b). Such models of providing service and funding are theoretically designed to offer a greater choice and control to disabled people and their families over the services they receive and/or purchase. However, as discussed later in this thesis, at practice level, the decisions of the policy makers responsible for developing these service models are influenced and driven to a greater extent by economic considerations. Thus, significant efforts are invested in striking a balance between “ideal” support (theoretical influence) and “affordable” support (economic influence); and exploring other avenues such as people’s informal support networks becomes necessary to reduce the gap between the two. For example, as will be detailed in Chapter 4, in New Zealand, one of the initiatives under the Ministry of Health (MoH)’s “New Model” for supporting disabled people called “Local Area Coordination” aims to support disabled people and their families to identify and build networks within their extended family and community that could help them meet their support needs (Ministry of Health, 2016b). The kind of support that these networks could provide would fall within the definition of “informal support.”

On the other hand, in a developing country like India, as will be explained in more detail in Chapter 4, whilst some disability legislation and policies do reflect the theoretical advancements, at practice level there is little formal support and disabled people have very limited, if any, choice and control over the services on offer. Further, the state funding in the disability sector is very limited and, as a result, disabled people and their families are generally more reliant on their friends and extended family members to

⁴ As at June 9 2017, there were 174 ratifications/accessions and 160 signatories to the Convention including India and New Zealand (United Nations, 2017).
meet their care and support needs (Pinto & Sahur, 2001; Rehabilitation Council of India, 2014). However, to better support the disabled members of the community, the Indian government is gradually increasing its investment in the state funded rehabilitation and disability support schemes (Joydeep, 2013).

Thus, India and New Zealand represent those countries where disabled people and their families are generally more reliant upon informal and formal support, respectively. Further, the situation of these two countries also highlights the pressure the policy makers of both the developing and the developed countries experience in reviewing the mix of formal and informal support options in their services menu to get as close as possible to the ideal support whilst still keeping it affordable. Unfortunately, despite the efforts of the policy makers, the prevalent support models have been unsuccessful in meeting the needs of the end service users. Larkin and Mitchell (2016) argued that even the contemporary models of supporting disabled people are failing to adequately meet the support needs of all service users as there has been little policy consideration of family voice and choice. To find any workable solution towards bridging the gap between ideal and affordable support, it is important in the first instance to get a real understanding of what kind of supports disabled people and their families value as being useful. As elucidated by Oliver and Barnes (2012), it is about producing knowledge in the real world:

> As we move further into the twenty-first century it is increasingly apparent that the world faces unprecedented environmental, economic and political challenges that will almost certainly impact on the lives of disabled and non-disabled people in both rich and poor countries. Consequently our very survival may depend upon our ability to produce knowledge in the real world with which to address these issues. (Oliver & Barnes, 2012, p. 30)

Policy makers can gain this real world knowledge by consulting with people whose lives are affected before making crucial policy decisions. The need for consulting with disabled people and their families has been highlighted in the international disability literature time and again (Brown, 1994; Hewitt, Agosta, Heller, Williams, & Reinke, 2013; Moore, 1992; Rehabilitation Council of India, 2014; L. Sullivan, 2005; M. Sullivan & O’Brien, 2005; Wills, 1994). Further, this consultation needs to happen with different groups of disabled people about their individual needs rather than with just one
or two dominant and more vocal groups. When it comes to people with HCN, due to their limited cognitive ability and difficulties with verbal communication, they are often reliant upon their parents to speak up on their behalf. However, due to the demanding nature of their children’s everyday care (as mentioned earlier), these parents often have very little time and energy left to go and attend various consultation forums or get involved as activists as is common for some other groups of disabled people who are self-advocates. Moreover, a focused discussion on the specific support needs of the adults with HCN and their families is lacking in the international disability discourse as well as in the research literature. A number of researchers have reported that the support needs of the adults requiring ongoing care and support and their ageing parents have been poorly studied (James, 2013; Shaw, Cartwright, & Craig, 2011; Wong & Wong, 2003). Thus, due to a lack of representation, both in person and on paper, the voice of people with HCN and their families is often not heard. As aptly stated by Milner and Mirfin-Veitch (2012), “difficulty accessing the narrative of people with high and complex support needs has meant, however, that their subjective experiences are yet to inform the disability discourse….“ (p. iv).

This study makes its own contribution towards this identified need for further research and also towards bringing the voice and concerns of the parents of adults with HCN to the forefront.

1.2 Research aim and questions

The primary aim of this study is to understand the wishes and the worries of the parents of adults with HCN concerning their children’s future and the support mechanisms (both formal and informal) that they consider and value as being useful for their children’s future, with a view to making useful recommendations for design and delivery of disability services that cater to the specific support needs of adults with HCN and their families.

With the above aim in mind, the following two key research questions are identified:

1. What are the wishes and the worries of the parents of adults with HCN concerning the long-term care and well-being of their children?

2. What type of supports (both formal and informal) do parents consider as being crucial for their children’s future, especially when they are no longer there to care and advocate for them?
The study involves personal interviews with 14 parents in Auckland, New Zealand and 18 parents in Delhi, India. As mentioned earlier, India and New Zealand represent those countries where disabled people and their families are generally more reliant upon informal and formal support, respectively. Therefore, in addition to the reasons for my personal and professional connection with both countries (as will be alluded to in Chapter 5); India and New Zealand were chosen as the study sites with the primary purpose of providing a unique insight into what influence does living in countries with varied levels of formal and informal support have on the wishes and worries of the parents of children with HCN concerning their children’s long-term future.

The next section outlines the key concepts central to this study and the chapter ends with a brief overview of the structure of the thesis.

1.3 Key concepts

This section essentially explains how some of the key concepts are defined or understood in the context of this study.

1.3.1 Disability

There have been various approaches of understanding disability ranging from person-focused medical model to society-focused social model and, more recently, the relational and interactional models that contest that disability results from a combination of intrinsic and extrinsic factors. Shakespeare (2006) argues:

> Social modellists would claim that ‘medical modellists’ assume that ‘people are disabled by their bodies’, whereas they say instead that ‘people are disabled by society, not by their bodies’. I would argue that ‘people are disabled by society and by their bodies’. (Shakespeare, 2006, p. 56)

Future thinkers and writers may well come up with yet other model/s of viewing and understanding disability, as disability is an evolving concept, one that cannot be constrained within the bounds of a single definition. Besides, the experience of disablement is unique to each individual and the impact this notion of disability makes on a person’s everyday life is also different for each person. Some people might associate it strongly with their impairment whereas for others it might be a state of mind. For some it might be omnipresent affecting all aspects of their life; for some it might be
contextual and experienced in waves; and for others it might be completely insignificant. Then, why bother with a definition of disability?

The idea of disability as a single category – into which individuals with all types of physical, emotional, sensory, and intellectual impairments are routinely placed – has come into more prominent usage as a by-product of broad social insurance and social security schemes that have grouped previously distinct categories of individuals together in order to provide benefit packages within nation-states.

(Groce & Zola, cited in Groce, 2005, pp. 5-6)

Thus, a definition is often needed for administrative purposes. Further, Oliver and Barnes (2012) argue that it is crucial to assign meaning to, or have a common understanding of, any social concept because in a social world, human behaviour towards any social object is driven by the meaning assigned to that object. If disability is defined as a personal tragedy, disabled people will be treated as victims of that tragedy and social policies will work towards compensating people for their tragedy. On the other hand, if disability is defined as a social oppression resulting from attitudinal and physical barriers created by an uncaring society, then it will be viewed as a social problem and social policies will work towards removing those barriers. Thus, it becomes important to clarify the meaning that is assigned to a particular concept in a given context.

Therefore, this study does not endorse any single, existing, theoretical definition of disability as the most perfect definition or attempt to propose any new definition; it does, however, for the purposes of providing a context to the study, use a working definition of disability. The definition used for the purposes of this research is the one proposed under the New Zealand Disability Strategy (NZDS) 2001:

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments.

Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have. (Ministry of Health, 2001, p. 3)
In line with the above definition of disability, this study also adopts the following definition of the phrase “disabled people” as proposed by the UNCRPD. According to Article 1 of the UNCRPD, “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN General Assembly, 2006, p. 4).

There is one other important element worth noting about the concept of disability, and that is, the language of disability. The issue of appropriateness of language around disability is a highly contentious one and often gets debated in the global disability literature (Barnes & Mercer, 2003; Beatson, 2004; Mehrotra, 2011; Oliver & Barnes, 2012; Shakespeare, 2006; Stroman, 2003; Swain, French, & Cameron, 2003).

I am of the opinion that the terms “disability” and “disabled” have both passed their use-by date and there is a need to start using a more neutral terminology that is not so inherently negative and disempowering. A detailed discussion on my reasoning behind such a claim is beyond the scope of this study and hence I am conforming to the norms of popular usage. For the purposes of this study, I have preferred to use the phrase “disabled people” in favour of “people with disabilities” as I concur with Oliver and Barnes (2012) that “to accept the label ‘people with disabilities’ is to accept that disability is an individual rather than a social problem” (p. 6). The phrase, disabled people, is also in alignment with the intent of the NZDS 2001 which proposes that people do not have disabilities but they are disabled by a society (Ministry of Health, 2001). Even if we use a more neutral definition, such as the one described earlier by Shakespeare (2006), which suggests that people are disabled both by society and their bodies, in my view, the phrase, disabled people, better captures this dual impact than does, people with disabilities. I do, however, acknowledge that some disabled self-advocates prefer the language of “people first” and accordingly prefer the phrase, people with disabilities. I do, therefore, apologise to those who find the use of the phrase, disabled people, offensive or not helpful.

It needs to be noted that when quoting the participants of this study, the language used by them has not been altered to fit my views on the appropriateness of the language.
1.3.2 High and complex needs

There is no standard definition of the term “high and complex needs” (HCN). For the purposes of this study, people with HCN include those who have one or more types of significant physical, cognitive or communication impairments and, as a result, require ongoing care and support in various aspects of their life including personal care and decision making. Other terms used for this group of people include “severely disabled people”; “people with high support needs”; “people with multiple disabilities”; or “people with profound disabilities.”

The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) (American Psychiatric Association, 2013) provides a description of the characteristics of this group that is widely accepted. According to the DSM-5, intellectual disability is “a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains” (American Psychiatric Association, 2013, p. 33). It also specifies four levels of severity of the disorder namely; *mild*, *moderate*, *severe* and *profound*. People with HCN referred to in this study fit the DSM-5 description of people with *severe* and *profound* levels of intellectual disability characterised by limited conceptual and social skills; lack of decision making abilities; and dependence on others for most aspects of their daily living including meals, bathing and dressing. The definition used in this study includes all people with such functional limitations irrespective of the age of onset.

It should be noted that the phrase, severely disabled people, was used in the initial promotional material for my research and during the interviews. However, during the field work, one of the key informants with a lived experience of disability suggested that the phrase, severely disabled, has a “stigmatising tone to it” (Mr K, Auckland key informant) and recommended that I use a phrase along the lines of people with high support needs. Therefore, the phrase “people with high and complex needs” has been used throughout the thesis except for the direct quotes from the participants. This phrase suggests that the support needs of this group of people are not only high but also complex due to the nature of their impairments and/or associated medical conditions.

1.3.3 Formal support

This study adopts the following definition of formal support as provided by the Office for Disability Issues and Statistics New Zealand (2013):
Formal support for a disabled person is assistance with everyday activities or living that is provided by people or organisations not generally related to the disabled person – through ties such as family relationships or friendship. Providers of formal support are usually paid for their services. These include: care services, help with household tasks, advice, special equipment/technology, environmental modifications, or other types of assistance. (Office for Disability Issues & Statistics New Zealand, 2013, p. 8)

Thus, formal support includes all forms of publicly funded products and services including financial support that may be available to disabled people and their families.

1.3.4 Informal support
According to Quinton (cited in Hatton et al., 2004), informal support is “the support given by people’s relatives, friends, neighbours and other organisations outside the service system such as religious organisations” (p. 67). Similarly, the Department of Human Services (2014) defines informal support as “the type of support that people get from family members or other supporters (not from paid carers)” (p. 88). Based on these definitions, in this study the phrase, informal support, includes all voluntary sources of support that disabled people and their families can access without a direct monetary cost. Informal support is also often referred to as “natural supports” (Duggan & Linehan, 2013) or “social supports” (Leach, 2015).

It should be noted that alongside “support”, the term “supports” is also used throughout the thesis to refer to various kinds of support (practical assistance) or services that could be provided by people from both formal and informal networks.

The next section provides an overview of the remaining thesis chapters.

1.4 Overview of research methodology
This study began with an idea generated from my personal and professional experiences of working in the disability sector in both India and New Zealand. A review of the relevant literature, combined with my constructionist epistemological position, helped me shape that idea into workable research questions and to clarify my research aim. The research questions combined with an interpretivist theoretical perspective and a rights based conceptual framework, in turn, guided my choice of a qualitative approach as the research methodology.
Fourteen parents from Auckland, New Zealand and 18 parents from Delhi, India were selected as the participants for this study using purposive sampling. Semi-structured interviews were conducted with these parents with a view to understanding their wishes and worries concerning long-term care and wellbeing of their adult children with high and complex needs; and ascertaining their views on the support mechanisms (both formal and informal) that they consider to be, and value as being, useful for their children’s future. Six key informants from New Zealand and seven key informants from India were also interviewed with a view to getting additional perspectives on the issues raised by the parents and to assist with providing robust recommendations. All the interviews were audio recorded and self-transcribed. Finally, thematic analysis of the data was conducted using NVivo™, a form of qualitative data analysis software, to generate findings. Chapter 5 provides a detailed, literature-based discussion on the methodological approach adopted in this study including a justification for selection of the methods of data collection and data analysis outlined above.

1.5 Thesis structure

This chapter provided background context to the purpose of this study and explained some of the key concepts central to the study. Chapter 2 provides a brief discussion on some of the general challenges associated with parenting a disabled child and some specific challenges that the parents encounter when supporting an adult child with HCN. The chapter highlights that parents often end up playing multiple roles in their disabled children’s lives with their sole focus being ensuring that their children’s support needs are met adequately.

Based on an extensive review of the literature, Chapter 3 provides a unique insight into how the elements of rights, choice, and support intertwine with each other using the UNCRPD as the backdrop for the discussion. Examining the relationship between these elements in contemporary society, the chapter highlights that people’s rights, their support needs, and the choices they are given or the choices they make could not, and should not, be seen in isolation from each other. This chapter provides a rights based theoretical and conceptual framework for the entire study including the methodological decisions related to the conduct of the study and the analytical discussion surrounding the findings of this study. The chapter also discusses specific implications of neoliberalist and capitalist worldviews on the rights of people with HCN to receive adequate support and having a choice while receiving those supports.
Chapter 4 provides a brief overview of the disability related legislative and policy framework and the formal support services structure in New Zealand and India. The chapter highlights that, with better access to various formal services covering all aspects of a person’s life, disabled people and their families living in New Zealand are generally more reliant upon formal support; whereas, due to limited formal support and the traditional family-oriented nature of that society, those living in India are generally more reliant upon informal support of their family and friends.

In addition to providing a detailed explanation of the key research elements that guided my choice of methodology and methods to conduct this study, Chapter 5 discusses the ethical considerations central to this study and also acknowledges the key limitations and assumptions of the study. Guided by the interpretivist theoretical perspective embedded in the constructionist epistemology and the rights based conceptual framework, a qualitative methodological approach was chosen to conduct the study. A detailed overview of this approach and the relevant methodological decisions will be outlined in this chapter.

To ensure that the voice of the parent participants gets prominence, Chapter 6 presents the findings of the study under appropriate theme-based headings using only the participant quotes, and a detailed analytical discussion of the findings is presented in Chapter 7 under the three broad sections titled “Desired future”; “Desired supports”; and “Desired changes.” The section on desired future provides insight into the research question on the wishes and the worries of the parents concerning the long-term future of their children. Similarly, the section on desired supports provides some answers to the second research question around the support mechanisms (both formal and informal) that the parents consider to be crucial for the future support of their children after the parents die. Finally, the desired changes section assists in fulfilling the key aim of the study by providing some useful recommendations around the role of the parents and the state in securing a better long-term future for people with HCN.
Chapter 2. Parenting a disabled child

The hallmarks of resilient families are pragmatism (being realistic, down-to-earth, practical), belief in your child, and vision (seeing long-term potentials and possibilities). This combination of characteristics builds a sense of security, self-confidence, and a taste for adventure in children (Kriegsman & Palmer, 2013, p. 3).

Maintaining this combination of pragmatism, belief in the child and a vision becomes a bit difficult for the parents when there is a disabled child in the family. Despite their best intentions, the parents get so caught up in the day-to-day struggle of meeting the immediate needs of their child that they often become too pragmatic (practically oriented), tend to lack belief in their child and avoid thinking about the future for their child. Since this study is about the parents’ vision of the future of their adult disabled children, it becomes crucial to provide a brief background to the predicament of these parents in raising their children. This chapter begins with a brief discussion on some of the general challenges associated with parenting a disabled child followed by a section that highlights some specific challenges that the parents encounter when supporting an adult child with HCN.

2.1 Being a parent of a disabled child

Parenting a disabled child is reported time and again in numerous studies to be far more complex and stressful than raising a non-disabled child (Bennett, 2002; Harrison, Henderson, & Leonard, 2007; Read, 2000; Walker, Baker, Sewell, Fleming, & Ramos, 2000; Wills, 1994). Further, it has also been recognised that the role that the parents of disabled children play in their children’s lives extends much more beyond the traditional role of just being a parent. It is argued that:

Parents whose children have disabilities assume or are expected by professionals to assume perhaps eight roles…. Parents as – (a) the source of their child’s problems, (b) organisation members, (c) service providers, (d) recipients of professionals’ decisions, (e) learners and teachers, (f) political advocates, (g) educational decision-makers, and (g) family members.

The parents do not get to choose any of these roles. Parents of other children are not subjected to them. Why should we be? (Turnbull & Turnbull, cited in Wills, 1994, p. 286)
Having to play such varied roles certainly takes its toll and as a result can often have an adverse impact on the parents and on the family unit as a whole. The issues faced in raising a disabled child as reported in studies with both sets of parents (Walker et al., 2000) as well as those done specifically with the mothers of disabled children (Bennett, 2002; Read, 2000) and the fathers of disabled children (Harrison et al., 2007) have been very similar and include:

- difficulties in managing work–life balance including limited choices in type of work and recreational activities they can engage in;
- feeling of losing their own identity other than being a parent of a disabled child;
- stress in relationship with their partners/other family members;
- loss of friends and feelings of isolation;
- poor health outcomes;
- worries about what would happen to their child if something happened to them.

On the other hand, some parents have also reported positive impacts from being a parent of a disabled child. For example, in a study of 12 West Midland mothers of disabled children (Read, 2000), many mothers reported that having a disabled child had made them a better person and appreciative of the struggles of other vulnerable groups. The mothers also felt that being an advocate for their child had made them more confident. Similarly, in her study with six mothers of disabled children, Bennett (2002) found that the mothers were very resilient despite the challenges faced by them. Thus, whilst it is often more stressful and complex to parent a disabled child, there are parents who embrace the positives and learn from their life experiences.

2.2 Parenting an adult child with HCN

Based on the definition of HCN used for this study, people with HCN have significant cognitive impairment and are often non-verbal. Therefore, before we look at the practical aspects of parenting an adult child with HCN, we need to acknowledge that one of the greatest challenges faced by the parents of adults with HCN is claiming and protecting their adult children’s fundamental rights to respect, dignity and citizenship.

Referring to the philosophical literature, Vorhaus (2014) stated that:

> According to a tradition going back to the Stoics, every human being has dignity just in virtue of having rational capacities, and the dignity of reason is worthy of
respect wherever it is found. But this leaves people whose rational capacities are constrained as vulnerable to the view that they might somehow not merit the respect owed to those possessing ‘the dignity of reason’. (Vorhaus, 2014, p. 614)

He then argued against such philosophical beliefs by claiming that the limited rationality exhibited by those who are “profoundly disabled” in the context of having an affectionate relationship with their parents and carers is still worthy of respect and dignity equal to those with higher rational capacities (Vorhaus, 2014). Another argument presented from a parent perspective is that, for adults with HCN, their parents and carers become the holders of their dignity. As explained by Trish, mother of Christiejane:

I need to hold her dignity for her. I wanted only women handling her. I didn’t want a male carer cleaning her nappy pads… Of course, Christiejane wouldn’t understand these concepts, and couldn’t protect her dignity herself. ‘Respect for dignity’ is trying to understand the world from Christiejane’s perspective. (Trish, cited in Vorhaus, 2014, p. 615)

Similarly, the notion of citizenship and how it applies to people with HCN is also worth exploring. Kjellberg (cited in Vorhaus, 2014) asserted that “respecting a human being as a person is one thing; respecting her as a citizen is another” (p. 615). The UNCRPD aims to shape a society that fosters participation of all disabled people as equal citizens (UN General Assembly, 2006). However, participating as a citizen often implies political participation and communicative competence. People with HCN often lack both. Vorhaus (2014) demanded the recognition of the citizenship of people with HCN and other similar groups in the following words: “[t]hese persons make up a significant proportion of our population, and we owe it to them to provide a conception of citizenship that does better justice to their lives than any whose primary dimension is participation in political decision-making” (p. 618).

Parents of people with HCN do the job of communicating on their children’s behalf and, as such, also become the guardians of their citizenship in addition to being the holders of their respect and dignity. The mothers that took part in Read’s study reported that “the erosion of their sons’ and daughters’ well-being and sense of self-worth is an ever-present danger which calls for vigilance” (Read, 2000, p. 106). As explained further in the next chapter, in addition to the risk of erosion of the sense of self-worth alluded to earlier, a lack of recognition of their rights to respect, dignity and citizenship also often
results in people with HCN not getting the appropriate support that they need to live a good-quality life.

Having discussed the parents’ role in upholding some of the fundamental rights of their children, it is now time to discuss some practical aspects of parenting an adult child with HCN. Disabled adults, in general, require more support services involving more government agencies than those required by younger disabled children. The needs of adults with HCN are even higher as they often have other associated health related conditions and behavioural issues requiring constant care and supervision, including attending to their intimate personal care (Hewitt-Taylor, 2008). As parents get older and their adult children become physically bigger and stronger, caring for them becomes more and more difficult – especially when they need personal care requiring lifting or they have behaviour problems of an aggressive nature. Thus, for the parents of children with HCN, the impact on the parents’ lives of raising a disabled child (as reported in the previous section) continues beyond their children’s childhood right up to their adulthood. They often do not get to do things for themselves that others can, such as taking vacations and pursuing hobbies that require time away from home. These parents’ lives become captive to their disabled children’s needs.

According to Morgan (2009), on average, disabled adults leave their parental house much later than those who are non-disabled. For adults with HCN this period may be even longer, if in fact they do leave the house at all. Using the metaphor of a nest, Morgan (2009) suggested that the parents of a disabled child may gain an extra bedroom when their child leaves home (say to live in a group home or in an independent living situation) but the “nest may never be empty” (p. 12). Even after their disabled children move, parents may be involved in ongoing training of support staff, or if they employ their own staff, they may end up looking after their adult disabled child when the staff have an unexpected leave of absence or leave the service. Thus, “the nest may not always be in your [parents’] own home, but your [parents’] involvement in keeping it warm and safe may continue forever” (Morgan, 2009, p. 13).

Parents of adults with HCN also face challenges with accessing services. For example, finding the right residential and/ or vocational programme for a person with HCN is more difficult as the noise and activity level in a group home or day centre may be too overwhelming for them; or a programme equipped to deal with the person’s behaviour
may not be able to deal with multiple medical needs too. Each person with HCN is unique and can function well if his or her unique needs are met in a certain way. Those certain ways of doing things become second nature for parents by the time the child becomes an adult and hence they either prefer to get involved (or are expected to be involved) in various service-related decisions. Thus, irrespective of where their children live, the battles faced by the parents of adults with HCN are never-ending; whether that be providing personal and physical care at home or fighting constantly for accessing and maintaining appropriate services that meet the unique needs of their children.

2.3 Concluding remarks
This chapter highlighted that parenting a disabled child is often more stressful and demanding than raising a non-disabled child, and raising a child with HCN is even further complicated due to their total reliance (which continues through their adulthood and beyond) on the parents for all aspects of their lives. Maintaining resilience in the face of such multiple complexities is not an easy task. It is only natural then for the parents of adults with HCN to be concerned about what would happen to their children if something happened to the parents. Unfortunately, some parents get so concerned about their children’s future after they (the parents) die that they “often express the hope to survive the child by at least 5 minutes, so it won’t be a problem. Some parents have actually taken tragic steps to assure they survive their child” (Morgan, 2009, p. 20). However, most parents of adults with HCN manage to do the job of caring and advocating for their children tirelessly and with as much grace as is humanly possible.

The next chapter explores the notions of rights, choice, and supports and argues that an understanding of how these concepts interact with each other and how that interaction impacts upon people’s lives is necessary to adequately support adults with HCN and their families.
Chapter 3. Triangulation of rights, choice and support

Many of the advances that have taken place in the disability sector over the last few decades began with the DRM activists demanding more choice and control over the supports they receive as a matter of right. However, due to their limited cognitive ability, the people with HCN often struggle to understand concepts such as rights and choice and hence their parents end up advocating for their right to support. Since this study concerns the future of adults with HCN when their parents are no longer alive, it becomes essential to have a thorough understanding of these concepts of rights, choice and support and their interaction with each other at service level to understand their combined potential impact on the lives of people with HCN whose parents are no longer alive. Essentially, this chapter provides a rights based theoretical and conceptual framework for the entire study including the methodological decisions related to the conduct of the study and the analytical discussion surrounding the study’s findings.

When it comes to a discourse on the rights of disabled people, the UNCRPD is considered to be the most comprehensive and powerful document of all time (Bickenbach, 2009; Oliver & Barnes, 2012). Since both India and New Zealand are signatories to the Convention, throughout this chapter references are made to various articles of the Convention that are relevant to the discussion. The chapter begins by unpacking the notions of rights, choice (and associated control), and support in a global disability context with a view to understanding how these concepts both interact and intercept with each other in practice. It then discusses the implications of the triangulation of rights, choice and support on the lives of people with HCN and their families. The chapter concludes with an assertion that, to design policies and service delivery models that can convert the rhetoric of rights from that of the theoretical to the tangible for people with HCN and their families, it becomes vital that the policy makers of all countries (rich and poor) listen to their voices and respect their choices.

3.1 The notion of rights

Despite Article 25 of the Universal Declaration of Human Rights 1948 offering various fundamental human rights to disabled people including “necessary social services and the right to security”, disabled people were excluded from the mainstream rights agenda during 1950s and 1960s. (Oliver & Barnes, 2012, p. 148)
One of the probable reasons for such exclusion could be that, in practice, equal rights were afforded only to those who were considered equal, but disabled people (alongside women and blacks) were considered different and hence unequal (Fredman, 2005). However, to argue that these groups of people are not different and hence should qualify for equal rights also has its own problems:

Treating two people alike, where one comes to the situation already burdened with disadvantage, will do no more than perpetuate the disadvantage.... Instead of requiring disabled people to conform to existing norms, the aim is to develop a concept of equality which requires adaptation and change. (Fredman, 2005, pp. 202-203)

Developing a concept of equality where adaptation was required by one part of the society formed the basic premise of the social model of disability that originated within the UPIAS (Union of the Physically Impaired against Segregation) during the 1970s. According to Carmichael (2004), the social model paved the way for disability to be seen as a human rights issue of equality and for disabled people to align themselves with other oppressed groups. This prompted a focused discussion on disability rights resulting in a growing range of anti-discriminatory legislation for disabled people being passed in many countries. This included various international declarations on the rights of disabled people during the last three decades of the 20th century. However, these laws and treaties did not achieve much in terms of how disabled people were treated, both by society in general, and by the policy makers in charge of making service-provision decisions. The answer to this failure, in part, can be found in Fredman’s analysis of “individualism” vs. “minority group rights” vs. “universalism” views surrounding the discourse on rights.

According to Fredman (2005), individualism demands that people should be treated as individuals in their own right regardless of the group they belong to. However, it also then treats discrimination as an individual problem as opposed to a systemic discrimination by a society against a particular group of individuals. If discrimination is to be viewed as something that happens to a group, the focus of the rights discourse then changes from individual rights to the rights of a group that the individual belongs to. This is what Fredman (2005) calls the “minority group rights analysis” (p. 204). Whilst such an analysis may be valid in the context of gender and race discrimination, its
application in disability context is a bit problematic. It views disability as a “group-defining characteristic” and therefore,

unintentionally reinforces the medical conception of disability, necessitating a view of disability as fixed and dichotomous; either one has a disability or one does not. The ways in which an impairment impinges on one’s life must be quantifiable once and for all. (Fredman, 2005, p. 206)

The social reality, however, is that disability unlike one’s gender – for example, female; or the colour of one’s skin, for example, black; is not a fixed characteristic and also disabled people with different types of impairments do not form a unique or a united group. It is this discrepancy between the social reality and theoretical foundations of minority group rights analysis that led in part to the earlier-described failure of disability legislation of the 20th century achieving its aims. Fredman therefore argued that “disability legislation needs to move away from the minority rights approach and instead promote a universalist view” (Fredman, 2005, p. 207).

According to Fredman, the rights of disabled people or other minority groups can only be recognised by adopting a universalist approach to rights that promotes substantive equality in which “the concept of equality is reconfigured, so that the norm itself is refashioned to incorporate social diversity” (Fredman, 2005, p. 213). The UNCRPD is based on such a universalist approach to rights. According to the UN Ad hoc Committee on the Rights of Persons with Disabilities, 2003 (cited in Fredman, 2005, p. 207), “disability is a normal aspect of life; all kinds of disabilities can happen to all types of people at all stages in their normal lifecycles.” In other words, the UNCRPD does not only recognise disability as part of social diversity but also acknowledges diversity within disability. Accordingly, when it comes to economic, social and cultural rights as enshrined under the Convention, all disabled people having equal rights does not mean that they get equal support but get supported according to their own unique needs so that they can live and participate in the community on an equal basis with others (a phrase often used in the Convention document). Thus, states need to acknowledge and realise that providing for the impairment-specific needs of the people with HCN may require a significant additional financial investment.
3.2 The notion of choice

The harshest reality about choice when it comes to disabled people is that they often do not even get to choose whether they are disabled or not:

Disability is socially constructed. For example, if a particular culture treats a person as having a disability, the person has one. Second, the category ‘disability’ includes people with socially defined functional limitations. For instance, deaf people are considered disabled although many deaf individuals insist they do not have a disability. People do not get to choose whether they have disabilities. (Charlton, 1998, p. 8)

Further, within the disability context, the notion of choice or a person’s ability to make a choice, often gets confused with that person’s perceived independence. For example, it is often assumed by service providers that if someone is not independent enough to look after own self-care, then that person is not competent enough to make a choice or any decisions about self-care. A part of the reason why this happens is due to the difference between how professionals and disabled people define independence. “Professionals, for example, have tended to define independence in terms of self-care activities such as washing, caring, toileting, cooking and eating without assistance...” (Oliver & Barnes, 2012, p. 136). Disabled people, on the other hand, may define independence to mean “having control over your life, not ‘doing things without help’” (Mason, cited in Oliver & Barnes, 2012, p. 136).

When defined as being able to have control over one’s life, true independence can only come when people can make their own choices and have a say in decisions affecting their lives. In other words, having a choice (and hence being able to exercise some control) can make people mentally and emotionally independent whilst still being physically dependent. However, going by the professionals’ definition of independence, only those disabled people who are independent in self-care despite their impairment would be considered capable of making a choice and hence worthy of being offered a choice. This would, in turn, deprive people who are physically dependent on others from experiencing even mental or emotional independence that having a choice could offer. Therefore, it becomes vital that “whatever the character and severity of an impairment, individuals must be empowered to make choices and exercise control in their everyday lives” (Barnes & Mercer, 2006, p. 184).
3.3 The notion of support

In the disability context, people often tend to use the terms “care” and “support” interchangeably. However, according to Oliver and Barnes (2012), “for many disabled people the concept of ‘care’ is both patronising and oppressive. Broadly speaking the verb ‘care’ means to look after or protect ‘with a definite implication of dependence’ in the person cared for” (p. 66). Therefore, the term “support” is generally more acceptable.

Moving on to what support means, just as there are differences in what independence means for disabled people and professionals, what constitutes support can also mean different things. Racino, O’Connor, and Walker (1992) suggest that “professionals view support more in terms of concrete actions that result in successful outcomes often defined on their terms” (pp. 360-361). When so defined, support can take the form of formal supports or informal supports designed to deliver outcome-oriented actions. As discussed earlier and elaborated further in the chapter to follow, disabled people and their families living in different parts of the world rely upon a varying combination of formal and informal support. Thus, whilst at a practical level, disabled people have to (and do) accept such notion of support, Racino et al. (1992) argue that “individuals with disabilities and their family members feel supported when they are listened to and understood from their perspective” (p. 358). The significance of this distinction between receiving support and feeling supported is explored further in the next section of this chapter.

3.4 The triangulation of rights, choice and support

The discussion thus far has highlighted the following key points about rights, choice and support. First, all disabled people have a right to be supported in a manner that, in consideration of their diverse needs, enables them to live and participate in the community on an equal basis with others. Secondly, irrespective of the severity of one’s impairment, people should be encouraged to make their own choices and exercise control over their own lives. And thirdly, in addition to getting practical support from both formal and informal sources, for many disabled people and their families, being supported also means being listened to.

In a global disability context, the concepts of rights, choice and support interact at a number of different levels. The UNCRPD (UN General Assembly, 2006) provides the
most direct link between the three as according to Article 3(a), it is based on the principle of “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices...” (p. 5); and Article 4(2) requires the states parties to take appropriate measures to realise economic, social and cultural rights prescribed under its various articles (UN General Assembly, 2006). Thus, freedom of choice and access to appropriate supports both form an integral part of the rights framework. The discussion now turns to some of the more complex aspects of the interaction between these concepts at a practice level beginning with a focus on the relationship between rights and support.

**Rights and support**

When it comes to the link between rights and support, a good place to start is to understand the difference between the prescribed level of obligations on the states parties towards realising disabled people’s fundamental human rights versus economic, social and cultural rights under the Convention.

According to the Article 4(1) of the Convention:

> States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

(a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention. (UN General Assembly, 2006, p. 5)

However, the obligations of the states parties in fulfilling the economic, social and cultural rights are somewhat less imposing. Article 4(2) of the Convention states that:

> With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources [emphasis added] and, where needed, within the framework of international cooperation, with a view to achieving progressively [emphasis added] the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law. (UN General Assembly, 2006, p. 6)
Linking this difference back to the professionals’ definition of support as being outcome-oriented actions, it is not so much the fulfilment of fundamental human rights but the economic, social and cultural rights that require the states to establish some sort of a support services framework. So, whilst disabled people do have these rights, states are not obliged to fulfil these rights fully (if they do not have enough resources) or immediately (so long as they work towards progressive achievement). The extent of a state’s liability to fulfil those rights and the duration of progressive realisation of the rights will differ from state to state and there is no way of telling (or contesting) whether a state is doing enough to meet its obligations under the Convention in providing adequate formal support.

Why then is a document so comprehensive is also so considerate when it comes to enforcing disabled people’s rights that require formal support services from the state? It is to do with costs. As Fredman (2005) explains, costs “constitute the hidden but powerful agenda behind much of equality policy and legislation. The ideals of equality and fairness are always tempered by a strong sense, amongst policy makers, that equality should not impose ‘burdens on business’” (p. 208). Thus, the intention behind the provision of progressive realisation of rights to the maximum of its available resources is presumably to avoid imposing an undue burden on the business, in this case, of the state parties.

Two factors that foster this notion of the burden of cost are the global dominance of capitalism over the world market and the neoliberal thinking that guide the welfare policies of countries, both rich and poor. For some time now, capitalism has become the dominant form of social organisation (Oliver & Barnes, 2012) and welfare provision conversations have been dominated by a neoliberal narrative (Kirk & Duschinsky, 2014). In such an environment, concepts of people’s rights, responsibilities, support needs and even problems (such as poverty or disability) are all viewed through the lenses of individualism inherent in both capitalism and neoliberalism.

Individualistic constructions of causality now shape political and personal landscapes as a way of both explaining social problems and developing solutions to those problems. Within this perspective, greater market ‘freedoms’, more ‘choice’ and the ability for individuals to ‘take control’ of their lives are considered the solution to social problems. (Kirk & Duschinsky, 2014, p. 79)
It is this idea of offering greater freedom, choice and control that has led to the 
emergence of independent living model or direct payment models of providing disability 
support services where the funding is given directly to disabled people and/or their 
agent/s as opposed to funding a service provider. Thus, under these models, a disabled 
person becomes both the user of the services as well as the purchaser of the services. 
Ideologically, it makes sense that one can purchase the service he or she wants to use. 
However, practical problems arise when the funds needed for purchasing those services 
are provided by someone else, in this case, the state. And when there is a pressure on the 
funding source, both the users and the purchasers of the services come under pressure. 
As explained in the following paragraphs, this becomes a double-edged sword for 
disabled people when they are both the users and the purchasers of the services.

Over the last decade or so, global capitalism has experienced its worst economic crisis 
and there is an increasing trend to cut back expenditure on public services. This impacts 
all sections of the society as “all life is dependent upon material resources for survival 
and human history is nothing less than a protracted struggle for access to and control of 
those resources” (Oliver & Barnes, 2012, p. 53). However, the implications of this trend 
of reducing public expenditure are greater for various marginalised groups, including 
disabled people. This is because, based on Fredman’s minority group rights analysis 
discussed earlier, once you define a characteristic of a group, it emphasises the 
distinctiveness of that group; and once people are seen as different, they end up 
“competing with the rest of the population” for access to finite resources to meet their 
different needs and wants (Fredman, 2005, p. 206).

On the other hand, Oliver and Barnes (2012) argue that, while new models of disability 
support may provide measures of control over people’s own lives and feelings of 
empowerment at some level, in a capitalist society, these models put disabled people in 
direct competition with other providers of services and force them to think like 
jobs and entrepreneurs. This may lead to disabled people making decisions that 
“make the most out of their buck” including buying a cheap product or service, 
especially when funding is limited.

Thus, this increasing global trend of reducing public expenditure has put disabled people 
in a situation of dual competition for accessing supports they need and the very 
framework that grants them a right to those supports falls short of providing them any
protection with its diluted obligations on the state parties of progressive realisation of rights within available resources. Thus, in a capitalist society, what disabled people get in the name of right to support is a double-edged sword without a scabbard.

Let us now focus on the relationship between support and choice.

**Support and choice**

As mentioned earlier, one of the principles under Article 3(a) of the Convention is respect for “individual autonomy including the freedom to make one’s own choices” (UN General Assembly, 2006, p. 5). The element of choice is also specifically mentioned in some other articles; for example, Article 19 suggests, “States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others [emphasis added]....” (UN General Assembly, 2006, p. 13). Thus, theoretically, disabled people should be able to make a choice about the support they require to realise various economic, social and cultural rights afforded to them under the Convention. However, in a real support service situation, irrespective of the model of funding, the power and control continues to remain in the hands of the professionals (Oliver & Barnes, 2012; Racino et al., 1992). For example, under the traditional residential model, service providers hold the power as the receivers of the funds:

Disabled people are usually offered little meaningful choice about aids and equipment; times at which professional helpers can attend to help with matters like toileting, dressing or preparing a meal are often predetermined; and the range of tasks that professionals can perform is limited because of professional boundaries, employer requirements or trade union practices. (Oliver & Barnes, 2012, p. 135)

Similarly, while disabled people may have some degree of control over the range and the timing of the support tasks under the direct payments model, their funding package itself is determined by the needs assessment and services coordination (NASC) agencies which, in turn, operate within certain prescribed financial boundaries. In other words, people’s stated needs for support at the time of assessment get redefined at the service coordination level through economic lenses and get translated into the service coordinators’ judgement of needs for services; and more often than not, the two do not
equate. Thus, even under direct payment models, the real “control” effectively lies in the hands of the NASC agencies as the gatekeepers of the funding.

A lot has been written in the last decade or so concerning the benefits, pitfalls and challenges of direct payment and independent living models (Morris, 2004; Scourfield, 2005; Shakespeare, 2006; Stainton & Boyce, 2004). For example, Shakespeare (2006) argued that, although desirable for many users, the direct payment model may not be suitable for all disabled people because ultimately it is the type of outcome desired by an individual that determines the appropriateness of the approach used to achieve that outcome. According to him, “[t]he different ends which different people value might include: control over one’s own life; convenience and lack of responsibility; safety and security; companionship and intimacy; routine and familiarity” (Shakespeare, 2006, pp. 150-151). Thus, for people who value other goals as more important than control over their own lives, the independent living model characterised by the direct payments method may not be the best option or an option of choice.

The relationship between choice and formal support also influences one’s choice of using informal networks as a complementary support option. Racino and Walker (1992) argue that:

Choice in the lives of people with disabilities is currently being translated into a form of consumerism where services are “individually packaged” and one “shops and buys” both services and workers. This approach perpetuates the market view of people’s lives... and detracts attention from the issue of the nature of relationships, power, and societal structures that can increase acceptance and support the opportunities for a range of lifestyle choices. (Racino & Walker, 1992, p. 74)

More than two decades later, this argument is still valid today and helps us understand why, at times, people are less inclined to choose informal support that can potentially offer more options in terms of real support. This notion of marketisation of people’s lives is very powerful and equally perilous. When care and the carer both become a commodity that can be bought and sold, it changes the nature of relationships and also influences what people do for each other in a natural relationship. In other words, preoccupied with an obsession of getting choice and control in receiving formal support, people often forget that “choice also must occur in the context of the relationships
people have with each other and the mutual and shared decision making such relationships imply” (Racino & Walker, 1992, p. 75).

Having explored the intricate relationship between rights and supports and supports and choice, it is time now to draw this section on the triangulation of rights, choice and supports to a close. Referring back to the basic link between the three concepts described at the beginning of the section, it is clear that freedom of choice and access to appropriate supports both form an integral part of the rights framework. Disabled people have a right to receive supports that are necessary to realise various economic, social and cultural rights afforded to them under the Convention, and at the same time should be able to make a choice in receiving those supports. However, as discussed, in reality their right to support is crippled by the progressive realisation clause of the Convention. Their freedom of choice is also often only as free as the service providers or the funds gatekeepers would allow it to be. Probably for these very reasons, at the time when everyone was overly enthusiastic about the magical powers of the impending Convention, Light (2005) was a bit sceptical about the changes it would achieve:

Without wishing to appear cynical, it is not the convention, but the resolve of states to give effect to our human rights, that will be decisive; it is not the letter of the law, but the determination to realise its aims that is crucial. The short answer is that the convention will achieve as much, or as little, as states are prepared to permit. (Light, 2005, p. 15)

It is unfortunate that Light’s scepticism is not far from the current reality as it is believed that the Convention has had very little real impact on the lives of disabled people. “It is becoming increasing apparent that having legal rights does not mean that they will be enforced and even if they are, that enforcement will achieve the desired aims” (Jolly, as cited in Oliver & Barnes, 2012, p. 151). It therefore becomes crucial that, while it is a legal framework, in an applied setting the Convention is also treated as a good practice framework. State parties should follow this framework out of a genuine desire to abide by its fundamental principle of respect for people’s inherent dignity, autonomy and freedom of choice in how the support services are delivered.

Figure 1 visually portrays the triangulation of rights, choice and supports.
3.5 Implications for people with HCN and their families

This section argues that the negative impact of the triangulation of rights, choice and supports on the lives of disabled people, as discussed above, is felt the most by people with HCN and their families. First, however, it needs to be established that the Convention is explicit about the support needs of people with HCN as well as the needs of families of disabled people. Item (j) of the preamble to the Convention recognises “the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support [emphasis added]”; and item (x) of the preamble recognises “that the family is the natural and fundamental group unit of society and is entitled to protection by society and the state, and that persons with
disabilities and their family members should receive the necessary protection and assistance...” (UN General Assembly, 2006, pp. 2-3). Further, in relation to long-term care and wellbeing of people living beyond the time of their parents’ death, Article 23(5) of the Convention provides for specific protection in stating that “States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting” (UN General Assembly, 2006, p. 16). Thus, theoretically, the Convention provides both implicit and explicit protection to people with HCN and their families.

At a practice level, however, some neoliberal concepts dominate the rights, choice and support discourse and unfortunately these are not very helpful when applied blankly to the situations of people with HCN and their families. One such concept is the assertion of a “reciprocal relationship between ‘rights and responsibilities’” (Oliver & Barnes, 2012, p. 123). According to this, for people to access social rights there is an expectation to contribute back to the society often through paid work. As Oliver and Barnes explain, “the policies that are based on unconditional entitlements to welfare benefits and support are perceived as promoting welfare dependency” (Oliver & Barnes, 2012, p. 124). The goal then becomes to discourage a culture of dependency which, in turn, legitimises policy decisions to cut welfare expenditure, sometimes beyond the legitimate needs of the citizens. Further, as mentioned earlier, in a neoliberal environment, both social problems and social solutions are individual focused. Accordingly, “recipients of welfare provision require help largely because of personal and individual failings” (Ferguson & Woodward, cited in Kirk & Duschinsky, 2014, p. 78).

Oliver and Barnes (2012), however, argued that disabled people cannot be blamed for their situation because the institutional discrimination against them in the labour market prevents them from getting appropriate jobs and as a result they are often forced to be dependent upon welfare benefits. Moreover, when it comes to people with HCN, they are unable to take certain responsibilities such as paid work even if they wanted to or were not discriminated against. The families of people with HCN too, find themselves in a similar situation. Dependency on the state often becomes inevitable for them as one or both parents have to stay home to look after the disabled child (Morgan, 2009). That, combined with the additional costs associated with the child’s impairment (for example continence, communication, or medical care related) puts significant financial pressure
on the family. This often does not leave any other choice for these families but to look towards the state for support. Thus, people with HCN and their families become the victims of the policies designed to discourage the culture of dependency through no fault of their own.

Another separate, but relevant, debate worth mentioning when it comes to the rights of people with HCN is the critique and defence of the social model of disability. As mentioned earlier, the social model paved the way for viewing disability as a human rights issue of equality. However, Shakespeare (2006), in criticising the focus of the social model on barrier removal and anti-discriminatory legislation argued that even in a discrimination-free, fully accessible environment, many disabled people will continue to require various other forms of support related to their particular impairment (for example; continence, communication or diet related) to either fully participate in society or to just live a good quality life in their own home.

On the other hand, Vasey (as cited in Oliver & Barnes, 2012) argued that:

>The social model is not about showing that every dysfunction in our bodies can be compensated for by a gadget, or good design, so that everybody can work an 8-hour day and play badminton in the evenings. It’s a way of demonstrating that everyone – even someone who has no movement, no sensory function and who is going to die tomorrow – has the right to a certain standard of living and to be treated with respect. (Vasey, as cited in Oliver & Barnes, 2012, p. 23)

Thus, this debate indirectly emphasises that, while people with HCN may not be able to reciprocate their responsibility of making a contribution to the society to an extent that the neoliberal policy makers would expect from welfare beneficiaries, they still have a right to receive adequate support that would ensure a certain standard of living.

Moving on to the relationship between supports and choice, earlier we discussed that, irrespective of the model of support, disabled people rarely get any real choice and control. When it comes to people with HCN and their families, the additional question that needs asking is: Do they really want (or care about) choice and control when receiving support?

The notions of choice and control have a completely different meaning for people with HCN. One might try to offer them a choice by asking
What would you like to do at the weekend?.... But even that doesn’t help much. Because:

If you’ve always done the same thing every weekend,

And you don’t know what clubs there are,

Or which places can you visit,

And you don’t even know what ‘entertainment’ means;

Then how can you choose? (Jackson & Jackson, 1999, p. 16)

Thus, for people who struggle in making the simplest choices about the most mundane matters, the models of support that claim to offer a higher level of choice and control may not necessarily be that relevant. Similarly, when people require assistance in performing daily physical tasks as well as decision making and emotional support, the independent living model’s assumption that care could be separated into practical tasks and emotional content does not hold true. Referring back to our previous discussion around different people valuing different things, for people with HCN the preferred goal may be that of safety and security or routine and familiarity over individual choice and control and therefore traditional models of care offering personal assistance may be more suitable for them.

Therefore, although all disabled people, irrespective of the severity of their impairment, should ideally be encouraged to exercise choice and control, individual assessment of people’s needs and goals becomes imperative in deciding what is best for them in practice. Expecting them to blindly acknowledge the ideology of control and choice and fit in to the models designed based on that ideology may not necessarily work. In summary:

One size will not fit all – either the historic form of residential care, or the current ideal of independent living. Whatever form of care and support is adopted needs to be based on respect for both parties – those who deliver care and support and those who receive it. (Shakespeare, 2006, p. 151)

3.6 Concluding remarks

This chapter highlighted that, whilst disabled people have a right to receive adequate support and also to a choice in receiving that support, the economic considerations
determine the level of support they receive and the real choice lies either in the hands of the service providers or the gatekeepers of the funds. Further, when it comes to people with HCN, the policy makers need to be mindful of various other factors. First, adopting the neoliberal thinking of *no rights without responsibilities* could disadvantage people with HCN and impinge upon their right to an adequate standard of living. Secondly, all disabled people should not be treated the same and it should be recognised that providing adequate support to people with HCN may require additional financial investment. Finally, it needs to be acknowledged that not all people with HCN and their families prefer choice and some might value other factors more than choice and control.

Therefore, going forward, to see any significant improvement in the lives of people with HCN, the policy makers of all nations need to: a) understand and adopt the universalist principle enshrined in the Convention; and b) refrain from using the one-size-fits-all approach.

To clarify the first point around the universalist view, it needs to be recognised that disability policy is “not policy for some minority group; it is policy for all” and in such a policy, “central is the call for justice in the distribution of resources and opportunities” (Fredman, 2005, p. 207). Thus, it is about viewing the Convention as a framework applicable to all sections of the society, not just a minority group of disabled people, and then giving due consideration to various articles of the Convention in designing policy initiatives, not as a legal obligation, but as a positive duty to promote and further the aims of the equality agenda and committing the resources to ensure its implementation.

Moving on to the second point, the message implied in avoiding the notion of a one-size-fits-all approach is that the policy makers need to make a conscious effort to understand the unique needs of different groups within the disability population so that the policies they design can appropriately cater to those needs. The best way to gain such an understanding is to involve all sections of disabled people and their families, where appropriate, in the decision making processes. This signifies the difference highlighted earlier in how professionals and disabled people define support. For disabled people, support does not only mean outcome-oriented actions but also means being heard from their perspective. The discussion chapter not only explains in detail the importance of consulting with the parents regarding future support needs of their children with HCN but also highlights a need for different model of partnership between parents and policy makers.
Chapter 4. Disability support services: An overview

This chapter provides an overview of the existing disability support services and relevant disability legislation and policies in New Zealand and India. It will provide the necessary background context to the findings chapter containing the information shared by the participants and the subsequent discussion of the findings in the concluding chapter. It may be noted that, since this study primarily concerns adults with a disability, the laws, policies and services that focus specifically on children with disabilities under 18 years of age have limited mention in this overview.

4.1 New Zealand context

In 1972, the recommendations of a Royal Commission enquiry into psychopaedic hospitals that disabled people should be supported to live in the community as opposed to large residential institutions marked the beginning of the deinstitutionalisation process in New Zealand. From that time, the government started to design and deliver services in a manner that would assist disabled people to live and take part in the community. In 2006, the closure of the last large institutional facility, the Kimberley Centre in Levin, marked the end of the three-decades-long deinstitutionalisation process.

The initial design of community based services, however, did not offer much choice to disabled people as the funding was primarily routed through disability service providers. Thus, the power largely remained in the hands of either the funder or the service providers. The operational nature of the community based residential services has been criticised as running “mini institutions” within communities (Social Services Committee, 2008). Further, as Beatson (2004) explains, another probable reason why not much positive change was seen in the lives of disabled people until the beginning of the current century despite them being supported in the community was because “disability was very much the Cinderella of social policy, largely neglected by her two step-sisters Health and Welfare under whose charge she was placed” (p. 6). Thus, a need for policy document with a sole focus on disability was felt necessary to achieve any significant improvement in the lives of disabled people in New Zealand. What the sector got in the bargain was not a legally binding policy but a good practice guide in the form of the New Zealand Disability Strategy (NZDS) 2001 (Ministry of Health, 2001).

Despite having no teeth in terms of enforceability, with the vision of a fully inclusive society enshrined in its 15 objectives, the NZDS 2001 gave new vigour to disability
advocacy in New Zealand. As explained in the sections to follow, the last 15 years has seen significant progress both in terms of policy and practice in the area of disability support, including the ratification of the UNCRPD by New Zealand in 2008.

To ensure that the rhetoric of choice and control in the decisions affecting their lives as promised by the NZDS 2001 and, as assured under the UNCRPD, translates into everyday practice, disability advocates in New Zealand have continued to lobby the government. In response, the government has allocated significant additional funding in recent years for disability support services and has also implemented various progressive initiatives under what they call a “New Model” for supporting disabled people (Ministry of Health, 2016b).

According to the New Zealand Disability Survey 2013, which provides the latest and the most comprehensive disability statistics, a total of 1.1 million people comprising 24% of the New Zealand population were identified as disabled (Statistics New Zealand, 2014). In the survey, just over half of all disabled people were identified to have more than one type of impairment, however, no precise population estimates are available on the people with HCN. The population estimates for this group of people are lacking even in the international literature (Te Pou o Te Whakaaro Nui, 2013).

The following sections provide an overview of the policies, legislation and services designed to support the disability population of one in four New Zealanders.

4.1.1 Key disability legislation, policies and strategies

In terms of disability related policies and legislation, New Zealand has made significant progress from the Lunatics Ordinance of 1846 to the New Zealand Disability Strategy 2016. Some of the key pieces of legislation and policy guiding documents of the last five decades are described below in chronological order.

**Accident Compensation Act 1972 and 2001**

Originally passed in 1972, this Act provided for a no-fault system of compensation and rehabilitation for people impaired as a result of an accident or injury. The compensation scheme became operational in 1974 with the establishment of the Accident Compensation Commission (ACC). The 1972 Act was repealed by the Accident Compensation Act 2001 and it has gone through a number of other amendments with the latest amendment being in 2016.
Disabled Persons Community Welfare Act 1975
Designed to make better provision for financial and other assistance in respect of the disabled, this Act was instrumental in establishing the first-ever comprehensive system of disability support services under the then Department of Social Welfare. Currently, the administration of the majority of disability services is governed by the New Zealand Public Health and Disability Act 2000.

Protection of Personal and Property Rights Act 1988
This Act is designed to help people who have limited capacity of making or understanding the decisions related to their own personal care and welfare or property, or when they are no longer able to communicate their decisions to other people. Its provisions allow a legally appointed welfare guardian to speak or make decisions on behalf of a person assessed as not being competent enough to manage his or her own affairs. This Act was last amended in 2013.

Health and Disability Commissioner Act 1994
The office of the Health and Disability Commissioner was established under this Act to investigate complaints related to the quality of health and disability services and it also established a nationwide health and disability advocacy service to assist service users to speak up for their rights. The Commissioner’s first task was to develop a Code of Rights and on 1 July 1996, the Code of Health and Disability Services Consumers’ Rights was established giving 10 rights to all health and disability service users. New Zealand is the first and the only country to have such a unique Code of Rights with a specific focus on the quality of health and disability support services.

New Zealand Public Health and Disability Act 2000
This Act transferred the responsibility for funding disability support services to the Ministry of Health. It governs the current funding in the disability sector for all non-injury-related support services.

New Zealand Disability Strategy 2001
The New Zealand Disability Strategy 2001 – Making a world of difference: Whakanui Oranga is considered “the single most important government initiative ever taken on behalf of the disability sector” (Beatson, 2004, p. 496). The vision of the strategy was to make New Zealand a fully inclusive society and provided a framework for the state to address disability issues through its 15 objectives. To lead the monitoring and
implementation of the strategy across various government departments, the Office for Disability Issues (ODI) was created within the Ministry of Social Development (MSD).

**Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003**
The primary purpose of this Act is to recognise and protect the special rights of people with an intellectual disability; and to provide courts with appropriate compulsory care and rehabilitation options for persons who have an intellectual disability and who are charged with, or convicted of, an offence.

**New Zealand Sign Language Act 2006**
With a view to promoting and maintaining the use of New Zealand Sign Language (NZSL), the preferred language of many Deaf New Zealanders, this Act declared the NZSL as an official language of the country. This declaration, alongside other provisions of the Act, is regarded as a significant victory for the advocates in the Deaf community.

New Zealand signed the Convention on 30 March 2007 and later ratified it on September 26, 2008. At the government level, the primary responsibility of coordinating with various agencies in relation to the implementation of the UNCRPD lies with the ODI. In addition, for independent monitoring of the progress on the implementation of various articles of the Convention, New Zealand developed an Independent Monitoring Mechanism (IMM) comprising of three independent and equal partners: the Human Rights Commission, the Office of the Ombudsmen and the Convention Coalition made up of seven disabled persons’ organisations (DPOs). New Zealand ratified the Optional Protocol of the UNCRPD on October 4, 2016, a move welcomed by the disability community.

**Disability Action Plan 2014-2018**
The Disability Action Plan 2014-2018 sets strategic priorities that advance implementation of the NZDS and the UNCRPD. The development of the plan followed a co-design process involving a collaboration between government agencies and the DPOs to achieve the shared vision of disabled people experiencing equal rights of citizenship (Office for Disability Issues, 2014). The action plan proposes to work towards five, person-directed outcomes namely, safety and autonomy, wellbeing, self-determination, community, and representation.
New Zealand Disability Strategy 2016-2026

Referring to the NZDS 2001, Beatson (2004) commented that the strategy “is strong on rhetoric, but weak when it comes to hard-nosed action plans for translating rhetoric into reality” (Beatson, 2004, p. xvii). The report of the Social Services Select Committee’s enquiry into the quality of care of people with disabilities also commented on the poor implementation of the strategy (Social Services Committee, 2008). In acknowledgement of the need for a more robust guiding document that included some specific actions, the government worked with the disability sector to develop a fully revised New Zealand Disability Strategy 2016-2026. Unlike NZDS 2001 that had 15 objectives, the NZDS 2016-2026 identifies eight outcome areas that will contribute towards achieving the strategy’s vision of creating a non-disabling society where “disabled people have an equal opportunity to achieve their goals and aspirations” (Office for Disability Issues, 2016, p. 6).

Thus, New Zealand has a varied range of laws and policy documents aimed at promoting and protecting the rights of disabled New Zealanders and to help them live a fulfilling life in the community.

4.1.2 Formal disability support services

Besides ACC (which covers all rehabilitation and support needs of people impaired as a result of an accident or injury), the two major funders of disability services for all other impairment types are the MSD and the MoH. A brief overview of the type of support services provided by both these agencies is provided below. It may be noted that the description of each type of support is primarily provided from the website of the respective funder and I have refrained from entering into a detailed discussion on the significance or otherwise of each type of support and the controversies surrounding some of the services.

Ministry of Social Development (MSD) funded support

In addition to the various benefits and payments available to all New Zealanders, the MSD also provides various specific assistance to disabled people and/ or their families through their department of Work and Income. Some of the key benefits are described below (Work and Income, 2017):
• **Supported Living Payment** – financial assistance for people who have, or are caring for someone with such a health condition, injury or disability that permanently and severely restricts their ability to work

• **Disability Allowance** – covers regular, ongoing costs because of a disability, such as visits to the doctor or hospital, medicines, extra clothing or travel

• **Child Disability Allowance** – payment made to the main carer of a child or young person with a serious disability. It is paid in recognition of the extra care and attention needed for that child

• **House Modification Funding** – payment which helps someone pay for changes to their home because they or their child have a disability

• **Accommodation Supplement** – helps people with their rent, board or the cost of owning a home. This is available to all New Zealanders who meet the criteria

• **Community Services Card** – helps to subsidise some health services and prescription costs. This is also available to all New Zealanders who meet the criteria

Over and above the direct income support to disabled people and their families, the MSD also funds a few other disability support services including family and community services, social and vocational services and employment assistance programmes.

**Ministry of Health (MoH) funded support**

For anyone wanting to access the MoH funded disability support services, their first point of contact becomes their local Needs Assessment and Services Coordination (NASC) agency. There are several NASC agencies throughout the country covering different geographical regions. A NASC agency assesses the eligibility of people for publicly funded services and does the assessment and coordination of the support needs for those who are eligible.

Some of the key disability support services available to disabled people and their families through the MoH are listed below (Ministry of Health, 2014a):

• **Community Day Services** – helps disabled adults who cannot find work to take part in their community and improve their personal skills by providing access to regular meaningful social contact and stimulating activities

• **Community Residential Support Services** – assists disabled people to live in a supported community environment
- **Home and Community Support Services** – designed to support disabled people to live at home, it may include assistance with personal care tasks (such as dressing, showering) and household management tasks (such as for cleaning and cooking)
- **Respite and Carer Support** – designed to help full-time caregivers of disabled people take some time out for themselves, while ensuring the disabled person continues to get the care and support they need
- **Individualised Funding** – enables disabled people to directly manage the resources they have been allocated for home and community support services and respite care
- **Supported Living** – helps disabled people to live independently by providing support in those areas of their life where help is needed – for example, support with shopping, budgeting, banking etc.
- **Funded Family Care** – a form of funding that allows some eligible disabled people to employ their parents or family members over 18 who they live with to provide them with their personal care and/or household management support

In addition, the MoH also provides equipment and modification services, behaviour support services, and Disability Information and Advisory Services (DIAS).

**The “New Model”**

The development of the “New Model” began in response to the recommendations of the 2008 report of the Social Services Select Committee’s “Inquiry into the Quality of Care and Service Provision for People with Disabilities” to make disability services more responsive to the needs of disabled people (Social Services Committee, 2008). “The New Model is new a way of supporting disabled people to achieve their goals. It gives people more choice and control over support and funding in their everyday lives” (Ministry of Health, 2016b, para 1). The model was developed in consultation with disabled people, their families and the wider disability sector and the first demonstration project under the New Model was launched in August 2011. It may be noted that the four key initiatives of the New Model described below are currently available only in certain regions of New Zealand but are intended to be made available throughout the country over a period of time (Ministry of Health, 2016b).

- **Local Area Coordination** – involves a coordinator working with disabled people and their families to develop a support plan identifying what represents a good life for them and then assisting them to identify resources within the family and
community to lead a good life. Anecdotally, this model is criticised by some as an effort to reduce the government funding in the sector.

- **Supported self-assessment** – replaces the traditional needs assessment done by the NASC agency and allows people to do the self-assessment of their support needs at a time, place and pace of their choosing. The completed self-assessment is then discussed with the NASC and used to identify appropriate disability supports.

- **Enhanced individualised funding** – unlike individualised funding that could be used only for home and community support services and respite care, the enhanced individualised funding gives disabled people more choice, control and flexibility in the way they use their disability support budget, by allowing it to be spent on a wider range of MoH funded disability supports.

- **Choice in community living (CCL)** – is an alternative to residential services, and aims to open up opportunities for disabled people and their family to have more choice and control about their living circumstances – where they live, who they live with and how they are supported.

In addition to the MSD and the MoH funded support services described above, there are a number of other agencies that get involved in funding support services for disabled people including the Ministry of Education, the Ministry of Transport, and the District Health Boards (DHBs). In response to the criticisms around the siloed approach of these agencies towards people’s lives, a new approach is being trialled called the “Enabling Good Lives” (EGL) project.

**The EGL project**

The EGL project was developed by pooling the funding from the three ministries (Health, Education and Social Development) with a view to providing more coordinated support and making it easier for disabled people and their families to create good lives for themselves. Key characteristics of the EGL model include self-directed planning and facilitation (by disabled people and their families); cross-government individualised and portable funding (with greater control over how the funding is spent); considering the person in their wider context (all-of-life and whole-of-life approach); strengthening families or whanau; and community building to develop natural supports (beyond people’s immediate informal networks) (Enabling Good Lives, 2017). It is these characteristics that make this project a very promising model of delivering disability support services in the future.
The EGL uses a principles approach and is guided by eight principles designed to assist all involved to ensure that the progress stays on track. The EGL’s first demonstration project started in 2012 and in the long term, “this approach may be used as the basis for changing the disability support system in New Zealand, alongside the New Model for Supporting Disabled People” (Enabling Good Lives, 2017, para 4).

Thus, it could be argued that, alongside supportive legislation and policy documents, New Zealand also has a reasonably well established formal support system to assist disabled people and their families to live a good life.

4.2 Indian context

Traditionally, in the Indian context, the term “family” referred to at least three generations of people including grandparents, parents, uncles and aunties and siblings, and cousins. “Care and consideration for the sick, elderly and disabled has always been a part of Indian culture and tradition. The core of this value system was the joint family and this extended to the village and community” (Rehabilitation Council of India, 2014, p. 3). Support from these family members, whether living under the same roof or not, was commonly expected and available. As explained by Racino et al. (1992):

Personal relationships are the source of concrete assistance for individuals with disabilities and families, as well as source of emotional support. People in relationships do a certain amount for each other that is considered a ‘normal’ part of their relationships.... What is typical for people to ‘do’ for each other in a relationship varies from one relationship to another. (Racino et al., 1992, p. 362)

It can be argued, however, that even within a relationship – for example, a parent and an adult child – what is typical to do for each other would vary depending upon what is expected of that relationship in a given culture. An adult child living at home with parents or a parent relying totally on adult children for financial support is common in India; whereas, in New Zealand, it would not be typical practice for a parent to provide extensive care and support to their children once they are over 18, particularly when they are non-disabled.

Therefore, as explained by Pinto and Sahur (2001), in the Indian context, the concept of creating long-term support systems that enable people to live independently in the community has a rather different meaning and should be approached with caution.
In a traditional country like India, where informal support is the norm and has been the only form of available care for thousands of years, great caution must be exercised to understand the real implications of the community care model being offered, in spite of how impressive it sounds. (Pinto & Sahur, 2001, [Community care], para.1)

Further, in India, disability is a small part of a much larger plethora of social issues. As Mehrotra (2011) explains:

In India and much of south Asia, disability is largely seen as a product of cultural impediments such as beliefs and stereotypes as well as structural impediments like poverty, lack of development, illiteracy, unemployment and caste, class and gender barriers. PWD [people with disabilities] are marginalised in education, employment, mobility and other significant life areas. The meaning of disability in India is embedded in this basic struggle for survival and cultural understanding. (Mehrotra, 2011, p. 66)

Finally, another crucial aspect to consider when it comes to disability support services in India is the size of the population. According to the 2011 census there were about 26.8 million disabled people in India representing 2.21% of the total population (Office of the Registrar General and Census Commissioner, 2013). It has been acknowledged that the process of collecting data on disabled people is not very reliable (Singh & Dash, 2014) and, as a result, it is suggested that more realistic estimates of disability population are much higher and stand somewhere between 70 to 100 million people (Rehabilitation Council of India, 2014).

The fact that the number of persons with disabilities in the country is not accurately identified leads to many issues. When numbers are not known, effective policy intervention and making budget allocations to meet their needs becomes difficult. This in turn will affect all other decisions concerning persons with disabilities. (Rehabilitation Council of India, 2014, p. 437)

Given this context of the societal structure and the size of the population, the advances that have been made so far, both at the policy and the practice levels, in promoting and protecting the rights of the disabled in India are significant and can be accounted for partly by the efforts of disability rights activists (Mehrotra, 2011) and partly to international influence (Pinto & Sahur, 2001).
The sections to follow provide an overview of the key legislation, policies and services designed to support disabled people in India.

### 4.2.1 Key disability legislation, policies and strategies

The Indian constitution provides certain fundamental rights that are applicable to all citizens. In addition, the country is divided into states and union territories which have their own governments, in addition to the central government. Thus, disability is both a central and state subject and, accordingly, there are both central legislation and policies as well as policies at the state level. The national level Acts enacted specifically for the welfare of disabled people are described below.

**The Rehabilitation Council of India Act, 1992**

The Rehabilitation Council of India (RCI) was established as a voluntary society in 1986 to standardize training programmes for special education teachers. In 1993, the RCI was granted the status of a Statutory Body by this Act to give it more powers to regulate and enforce the curriculum for various rehabilitation practitioners including special educators (Singh & Dash, 2014). “The Act basically lays down the mandate given to the RCI which covers the regulation of professionals, the standardization and monitoring of training, the recognition of institutions, the registration of professionals and personnel and the provision of research” (Rehabilitation Council of India, 2014, p. 20). The Act was amended in the year 2000.

**The Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act, 1995 (PWD Act)**

For a developing country like India, this Act was well ahead of its time and has been considered “ground-breaking” (The World Bank, 2009) and as “landmark” legislation (Singh & Dash, 2014). As the title of the Act suggests, it was aimed at providing better opportunities to people with disabilities, particularly in the areas of education and employment; to promote their full participation in the community through affirmative action in the direction of removal of structural and attitudinal barriers; and the promotion and protection of their rights. To achieve this aim, the Act mandated the establishment of the Office of the Commissioner for Persons with Disabilities at national and state levels to be headed by the Chief Commissioner and state level commissioners, respectively. The Commissioners were tasked with providing an oversight of the Act and being a watchdog for the disability sector. The Act also made provision for social
security in the form of funding for disability service organisations, unemployment allowance to disabled people, and provision for better health care and rehabilitation amongst other things. “The advent of this Act marked a watershed in the quality of life of the persons with disabilities in the country and heralded a number of progressive steps in the fields of education, training, barrier-free environment and a host of other services” (Singh & Dash, 2014, p. 33). The Act was, however, criticised for shortcomings in its design on the basis that the agencies responsible for its implementation were weak and under-resourced (The World Bank, 2009). This Act was repealed in 2016 and was replaced by the Rights of Persons with Disabilities Act, 2016.

**The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999**

Known, in short, as The National Trust Act, this is the most important Act pertaining to the topic of this study as it is designed primarily to put systems in place so that the people who are likely to require lifelong care in some form or other can continue to be supported well after their parents are no longer alive. “Parents always have the big question in their mind, ‘What will happen to our child after us?’ The National Trust Act is an answer to this question” (Singh & Dash, 2014, p. 37).

A National Trust was established under this Act with statutory powers to promote the welfare of the people with the specified disabilities with a view to helping them continue to live long term with their family or independently in the community; to provide support to the families in crisis; to support disabled people who do not have a family; and to provide for the care and welfare of disabled people in the event of the death of their parent/guardian. The trust was set up with a corpus fund of 10 million rupees provided by the Government of India and the income of the corpus is used to run the various programmes and schemes of the trust. The trust can also receive private donations from individuals and corporates.

**National Policy on Persons with Disabilities 2006**

Following criticisms that not much positive change had happened in the everyday lives of disabled people in the decade after the enactment of the PWD Act 1995, a draft National Policy for Persons with Disabilities was developed by the Ministry of Social Justice and Empowerment (MSJE) in 2005 and it was approved by the Cabinet in 2006 (Ministry of Social Justice and Empowerment, 2006). Founded on the belief that, with
equal opportunities and effective rehabilitation measures, people with disabilities can lead a better quality of life, the policy for the most part reiterates the commitments of the PWD Act. Although the policy mentions a provision for five-yearly reviews on the progress of its implementation, it has been criticised for not proposing more concrete strategies for implementation and for limited reference to the role of the disabled people themselves in its development, monitoring and evaluation (The World Bank, 2009).


India was one of the first few countries to sign (March 30, 2007) and ratify (October 1, 2007) the UNCRPD. However, the enthusiasm shown by the government in ratifying the Convention was lacking when it came to taking appropriate measures for its implementation. Disability was one of the smaller divisions within the MSJE, the ministry primarily responsible for the implementation of the UNCRPD. As a result, there was no strong focal point to coordinate with the other concerned ministries and guide them in fulfilling their respective obligations under the UNCRPD. After strong lobbying from the disability advocates, a separate Department of Disability Affairs was created within the MSJE in 2012 to act as a nodal agency for all matters pertaining to disability and people with disabilities. In 2014, the department was renamed as the Department of Empowerment of Persons with Disabilities (DEPD). India has not ratified the Optional Protocol of the UNCRPD as yet.

**The Rights of Persons with Disabilities Act, 2016**

In response to its ratification of the UNCRPD, in 2009, the government of India proposed several amendments to the PWD Act 1995. However, this proposal was severely criticised by the disability community and they demanded a totally new law that aligned with the UNCRPD. Kneeling to community pressure, a draft bill on the rights of persons with disabilities was developed in 2011. After several rounds of consultation with various concerned government agencies and the DPOs, India got its revolutionary Act: The Rights of Persons with Disabilities Act, 2016 (RPWD Act) which replaced the PWD Act 1995. The Act incorporates significant changes to help give effect to India’s commitment to the promotion and protection of the rights of its disabled citizens.

**Other international treaties**

In addition to the legislation and policies described above, India is also a signatory to:
• The Biwako millennium framework for action towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific; and

• The Incheon Strategy to “Make the Right Real” for Persons with Disabilities in Asia and the Pacific.

Thus, India has some very progressive policies and legislation aimed at the empowerment of disabled people and their families; however, more work needs to be done in the area of implementation at the ground level (Girimaji & Kommu, 2016; Rehabilitation Council of India, 2014).

4.2.2 Formal disability support services
Disability is both a central and state subject in India and hence different states have different levels and types of services on offer for disabled people. The DEPD located within the MSJE acts as the main nodal agency for coordinating the bulk of disability support services. This section provides an overview of some of the key central level schemes applicable to all disabled people in India.

Disability certificates/ identity cards
A disability certificate and/or an identity card is required for a person with a disability to avail themselves of any disability related facilities, concessions and benefits available under various schemes of government or non-government organisations (NGOs).

Disability certificates are issued by medical boards approved by the central and/or state government and they include details such as the person’s type of disability (for example, low vision) and percentage of disability (for example, 70%). Earlier, the certificates were issued only to people with seven disabilities recognised by the PWD Act 1995, however, with the advent of the RPWD Act 2016, many more disabled people will now be eligible for a disability certificate.

Vocational services
The Ministry of Labour has set up various Vocational Rehabilitation Centres (VRCs) throughout India to assist disabled people to learn different kinds of vocational skills and achieve economic independence. Various NGOs also provide vocational skills’ training to people with specific impairments – for example, the National Association for the Blind (NAB). The skills focus is on helping disabled people get jobs in the public or private sectors and also to gain some form of self-employment.
Rehabilitation services

The government of India has established the Artificial Limbs Manufacturing Corporation of India (ALIMCO) for the production and supply of necessary aids and equipment. Further, the MSJE has established nine national-level institutions to provide rehabilitation services to people with specific impairments – for example, the National Institute of Visually Handicapped (NIVH), the National Institute for the Mentally Handicapped (NIMH), and so on. These institutions also work in the area of early intervention and awareness raising related to the respective impairment.

In addition, the central government of India, with the support of the state governments, has established over 100 District Disability Rehabilitation Centres (DDRCs). These centres facilitate the implementation of various government schemes and programmes within their district including provision of disability certificates with the support of local resources and the expertise of the NGOs. Given the earlier context of the size of the population, it is not surprising that significant efforts are invested by the DDRCs in the area of prevention and/or early detection of disability. “It is also well known that only a fraction of financial outlay is needed to prevent disability from happening as compared to the huge budgets required to provide services to persons with disability” (Rehabilitation Council of India, 2014, p. 4).

Community Based Rehabilitation (CBR)

“Community Based Rehabilitation (CBR) is a process to bring about a transformation in the community to enable the community members to have a better understanding of disability services and to improve the overall quality of persons with disability” (Singh & Dash, 2014, p. 114). Since about 70% of the Indian disability population live in rural areas (Office of the Registrar General and Census Commissioner, 2013), the government recognises the importance of this approach and implements its CBR programmes through the NGOs. CBR programmes typically include activities such as surveys of disabled people in the local area; improving community awareness and attitudes through distribution of informative material, street plays, and seminars; and helping individuals and their families to access services and social security benefits and get involved in local communities (Girimaji & Kommu, 2016).
Social protection or benefits
Disabled people and their families also get some support through various central and state social welfare schemes in the areas of health care, employment and financial assistance. The level of support received differs from state to state but may generally include a combination of:

Reservations – in government jobs, housing schemes, higher education

Disability pension/unemployment allowance – for those unable to work as a result of disability

Social pension – a monthly cash benefit for “destitute” persons with disabilities

Insurance schemes – mainly health care related

Travel concession – for obtaining public transport at a subsidised rate

Income tax exemption – for working disabled people and/ or for the earning family member supporting a disabled person.

This is not an exhaustive list as there may be various other schemes and services especially at state level that are not well documented. It is, however, observed that the combined social protection offered to disabled people through various social welfare schemes appear to be rather insignificant (The World Bank, 2009).

Schemes of the National Trust
In addition to the various services described thus far, the National Trust also operates a number of schemes designed specifically for the welfare of people with the four disabilities under its mandate namely: autism, cerebral palsy, mental retardation and multiple disabilities. Based on the definition of HCN used for the purposes of this study, all people with HCN living in India will be covered by the National Trust Act and, accordingly, be eligible for the schemes of the National Trust. Some of their key schemes relevant for adults with HCN are described below.

Gharaunda (Group home for adults)
The objective of this scheme is to provide an assured home and minimum quality of care services throughout the life of the person (The National Trust, 2017a). The scheme allows registered organisations to set up group homes to support a “batch size” of 20 eligible disabled people per group home. The organisations are required to offer 50% of
their “seats” to people from lower income groups (LIGs) including those who live below the poverty line (BPL). The government provides the necessary funding to the organisations to support LIG and BPL people and the organisations are allowed to charge the parents, guardians or family members of the other (50%) disabled people living in their group homes. In addition to providing support staff to assist the residents with home and personal care, the organisations running the group homes are also required to provide basic medical care through professional doctors, vocational activities and training, and alternative therapies as needed.

**Samarth (Respite care)**

This scheme is designed to provide respite home care for disabled people who are orphans or abandoned; for families in crisis; and for disabled people from BPL and LIG families. Its purpose is to offer respite to the families that provide fulltime care to a disabled person so that they can fulfil their other responsibilities (The National Trust, 2017c). It operates in a similar fashion to Gharaunda and has a batch size of 30 people per Samarth home, 50% of whom should be from LIG and BPL families and the rest of the seats can be offered by the organisations to other people at a charge to maintain sustainability.

**Vikaas (Day care)**

With a dual objective of enhancing the interpersonal and vocational skills of people with disabilities and at the same time offering day-time respite to their family members, under this scheme, the National Trust funds registered organisations to run day-care facilities for at least six hours a day, five days a week offering various vocational and recreational activities (The National Trust, 2017d). The batch size of the scheme is 30 people per centre, 50% of whom should be from LIG and BPL families.

**Niramaya (Health insurance scheme)**

For all people with disability types covered under the National Trust, this scheme provides health insurance cover of up to ₹100,000 (just over NZ$2000) for medical treatment including out-patient treatment, hospitalisation, pathology/diagnostic tests, and therapies (The National Trust, 2017b).

**Role of the NGOs**

Given the spread of the disability population across various rural, hard-to-reach areas, the local NGOs play a major role in the disability sector in India. There are over 3000
NGOs providing various services to disabled people ranging from supply and distribution of assistive devices to awareness raising, advocacy, leisure and recreational activities to running micro-enterprises. These NGOs collaborate with the respective national institutes and the DDRCs in providing their services. The NGOs get some funding for the services they run under various government schemes but are largely dependent upon private donations including foreign funding to run their operations. It is therefore suggested that “it remains in many ways an under-exploited resource in terms of fully mature partnerships between the public and NGO sectors” (The World Bank, 2009, p. 138), and that “some measures are to be taken soon to break this deadlock to give impetus to the programme in the disability sector” (Singh & Dash, 2014, p. 161).

Thus, disability support services in India comprise, by and large, a complex web of numerous services offered by central and state governments and NGOs in different parts of the country. Various reports and literature published in the last decade or so on the status of disability services in India have all suggested that India has some very progressive legislation and policies when it comes to the rhetoric of the welfare of (and the promotion and protection of the rights of) people with disabilities (Girimaji & Kommu, 2016; Mehrotra, 2011; Rehabilitation Council of India, 2014; The World Bank, 2009). However, the same writers have also expressed their disappointment towards a lack of translation of rhetoric to practice on the grounds of: a weak institutional framework of implementation and poor accountability mechanisms (The World Bank, 2009); a lack of rights based approaches and inadequate support to the families (Girimaji & Kommu, 2016); and disabled-unfriendly attitudes and unsupportive bureaucracy (Mehrotra, 2011).

4.3 Concluding remarks

This chapter has provided a very broad overview of disability-related legislative and policy frameworks and the formal support services available to disabled people living in New Zealand and in India. It has highlighted that, whilst both countries have expressed their commitment towards the welfare of disabled people by signing and ratifying the UNCRPD, there are some significant differences, particularly in the nature and type of support services available at the ground level in both countries. A detailed discussion on the impact of these differences on the lives of disabled people is provided in the later chapters of the thesis.
I would like to conclude this chapter on a celebratory note that both the countries ended the year 2016 with significant milestones for the disability sector with New Zealand getting its revised and revitalised NZDS 2016-2026 and India enacting its revolutionary RPWD Act, 2016.

The next chapter discusses the methodology I adopted in conducting the research including an explanation of the methods used for collecting and analysing the data, a note on the ethical considerations guiding the study, and an acknowledgement of the key limitations and assumptions of the study.
Chapter 5.  Research Methodology

A good research study is one which has a clearly defined purpose, in which there is coherence between the objectives, the research questions and the methods or approaches proposed, and which generates data which are meaningful, robust and relevant. It is also, importantly, one which is realistic, conceived with regard both for practical constraints of time and money and for the reality of the research context and setting. (Lewis & Nicholls, 2014, p. 48)

The methodology that a researcher chooses to conduct a study determines how coherent the study is likely to be and whether or not the data generated are likely to meet the criteria of robustness and relevance that Lewis and Nicholls allude to above. The choice of methodology also has a significant bearing on the research outcomes because the quality of data has a direct impact on the quality of outcomes generated by the data analysis process. Therefore, to gain outcomes that “merit respect” (Crotty, 1998, p. 13) we need to justify our choice of methodologies and methods.

The focus of this chapter is on providing an overview of the research decisions I have made to conduct this study including a discussion of the factors that influenced my choices. In doing so, I have used Crotty’s (dated but seminal) framework that proposes that four key elements of any research process are epistemology, theoretical perspective, methodology, and methods (Crotty, 1998). The first three elements are discussed under the section titled “key research elements.” The final element, “methods” is then discussed in a separate section with specific focus on the methods chosen for sampling, data collection and data analysis. Towards the end, matters of ethical significance are discussed and the chapter concludes with an acknowledgement of the limitations of the study in view of the “practical constraints” and the “reality of the research context” that Lewis and Nicholls refer to in their definition (above) of a good study.

5.1 Key research elements

I have chosen to discuss the elements of epistemology, theoretical perspective and methodology together under this section because as we can see from the definitions provided below, they are strongly linked with one another.

Epistemology is “the theory of knowledge embedded in the theoretical perspective and thereby in the methodology” (Crotty, 1998, p. 3).
Theoretical perspective is “the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria” (Crotty, 1998, p. 3).

Methodology is “the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes” (Crotty, 1998, p. 3).

Based on these definitions, a researcher’s strategy and action plan of conducting the research (methodology) is informed by a philosophical stance that provides a contextual framework for the research (its theoretical perspective) which, in turn, is influenced by the way knowledge is theorised, or in other words, the way researchers understand and explain how they know what they know (epistemology). This relationship between epistemology, theoretical perspective and methodology is also affirmed by Broido and Manning (2002) as, according to them, “research can be understood as arising from particular paradigms that inform particular theoretical perspectives … that in turn shape choice of methodology” (p. 435).

This section also briefly discusses another important element, “ontology,” as it is often regarded “along with epistemology, as a foundational element of qualitative research” (Carter & Little, 2007, p. 1326). It is, however, suggested that research often begins with an idea (Berg & Lune, 2012; Lewis & Nicholls, 2014) that comes out of researcher’s personal experience (Bazeley, 2013). My research also began with an idea that came from my personal experience of working in the disability field for over twenty years. So, before discussing the influence of the above research elements on my study, I consider it necessary to provide a brief background to the genesis of my research topic.

5.1.1 Research background

I worked as a special education teacher in a special school for intellectually disabled children in Mumbai, India for about eight years from 1994 to 2002. During my tenure as a teacher, I had numerous opportunities for formal and informal interaction with the parents of my students. During those interactions, the topic of how they coped with their children at home was often discussed. On many occasions, whilst talking about the difficulties in managing their children at home, the parents (particularly those with a child with a severe disability) also expressed their concerns around their ability to manage their children once they were adults and over what would happen to their
children once they (the parents) were no longer around. At that point in time, I could not do anything about it other than sympathising with their situation.

I moved to Auckland, New Zealand in 2002 and started my first employment as a caregiver with a disability service provider. Unlike the special school in Mumbai where I primarily worked with intellectually disabled children of school-going age, I started working with adults with different disabilities including those with very HCN. During my six-year tenure with that service provider, I progressed in my job from caregiver to various other roles including house coordinator, day programme coordinator, and social services manager. All these roles also provided me with numerous opportunities for interactions with the families of people that our organisation supported. Even during those interactions, how the parents coped with their adult children at home (for those not using residential services) was often a topic of discussion. And again, in expressing their difficulties in managing their adult children at home, the parents (particularly those with a child with HCN) expressed their concerns surrounding what would happen to their children once they were no longer around. A *deja vu* feeling! But this time around, I was a bit more determined to do something about it, I just was not sure exactly what. By the time I finished working with that service provider, I had already completed my Masters in Social Work. I then worked for about five years with a Crown entity in the area of consumer rights. This role provided me an opportunity to learn a lot about provision of disability support services in New Zealand and its alignment, or otherwise, with people’s rights. I also had opportunities to interact with families at various disability forums and seminars and again I was invariably confronted with the parents’ concerns about their children’s long-term future.

So, finally when I decided to pursue my doctoral studies in social work, the choice of research topic was, to put it simply, an obvious one. I wanted to study, from a parent’s perspective, the question: What will happen to my child when I am no longer alive? This was, however, just the beginning – a research idea. I would now like to talk about the process I went through in converting that research idea into research questions and a purpose statement that are the driving force of this study.

**Researching the research question**

The literature review around an initial research idea helps to theoretically refine it and turn it into workable research question/s (Berg & Lune, 2012) and/or objectives (Lewis
I began researching this idea with a review of literature surrounding a number of related topics including: parenting a disabled child; parent experiences of working with support agencies and professionals; the role of formal and informal support in the lives of disabled people and their families; and the rights of disabled people and their families. The literature around these topics as discussed in chapters 2 and 3 helped me narrow down the focus of my research and become clear about the aim of my research. First, it helped me determine that I wanted to focus my study on the parents of adults with HCN so that the unique support needs of these families (which have received very little attention from writers and researchers alike), can be brought to the forefront. Secondly, given that they often have very limited say in the decisions affecting their lives (as elaborated in Chapter 3), it became important that my study focused on capturing parents’ voices – expressed through their views and thoughts on the type of future they envisaged for their children through their experiences and perspectives on how best their children could be supported after the death of the parents. Finally, it also helped me decide that, given the intrinsic role of economic considerations in whether these families get adequate levels of formal support, it was important to know how parents saw the role of informal support and its practical effectiveness when it came to supporting their adult HCN children when parents had passed on. This clarity over what I wanted to achieve in my study (guided further by my epistemological position, discussed in the next section) helped me shape the purpose statement of the study.

5.1.2 Epistemology and ontology

Epistemology is the theory of knowledge. Ontology, on the other hand, is “the theory of being” (Gomm, 2009, p. 114). Thus, ontology is concerned with the very nature of existence (Gray, 2009), the nature of reality (Carter & Little, 2007), or the nature of social entities (Bryman, 2012). In other words, ontology refers to “questions about what is meant by ‘existence’; what does exist and what is the nature of existential entities?” (Gomm, 2009, p. 114); and epistemology refers to “questions about how we know what we know, and how we can (or cannot) know what is true” (Gomm, 2009, p. 114). From an ontological viewpoint, some might believe that “reality and truth are external and exist, regardless of human interaction, while others may believe that reality and truth are socially-constructed” (Crowley-Henry, 2009, pp. 60-61). Epistemologically, the former group would then adopt a viewpoint that we can only know the reality (that is already
“out there”) by just objectively observing it; whereas the latter group would believe that to know the reality “which is an accumulation of our experiences and the meanings we associate with them” (Henn, Weinstein, & Foard, 2006, p. 17), a more interactive approach would be necessary.

My research began with an idea that came from my personal experience and the literature review around that idea helped me shape the aim of my research. However, as explained by Gray (2009):

> Despite the natural tendency for the researcher (and especially the novice researcher!) to select a data gathering method and get on with the job, the choice of methods will be influenced by the research methodology [emphasis in original] chosen. This methodology, in turn, will be influenced by the theoretical perspectives adopted by the researcher, and, in turn, by the researcher’s epistemological stance. (Gray, 2009, p. 17)

Thus, although guided primarily by my research aim and research questions, my choice of methodology and methods discussed in the sections to follow have also been influenced by my epistemological position. Whilst there seems to be consensus in the literature around the definitions of epistemology and ontology, when it comes to the various epistemological and ontological positions that researchers adopt, there are often contrasting views among authors. For example, according to Crotty (1998), objectivism and constructionism are epistemological positions, whereas to Bryman (2012) they are ontological positions. This could be because, as explained by Gomm (2009), “except at a very high level of abstraction it is difficult to untangle epistemology from ontology” (p. 114); and hence often the compound phrase “epistemological-ontological” is used by researchers to describe their position. Thus, although the discussion in this section primarily refers to epistemology, being the first element of Crotty’s framework, as explained in the discussion to follow, I have adopted constructionism as my epistemological as well as my ontological position for this study.

According to Crotty (1998), three main types of epistemologies are “Objectivism”, “Constructionism”, and “Subjectivism”. He defines them as follows:

Objectivism is the epistemological view that things exist as meaningful entities independently of consciousness and experience, that they have truth and meaning residing in them as objects. (Crotty, 1998, p. 5)
Constructionism is “the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, 1998, p. 42).

In subjectivism, meaning does not come out of an interplay between subject and object but is imposed on the object by the subject. Here the object as such makes no contribution to the generation of meaning. (Crotty, 1998, p. 9)

As a novice researcher, the advice given by Koro-Ljungberg, Yendol-Hoppey, Jude Smith and Hayes (2009) was particularly helpful in clarifying my epistemological position. They stated:

We would recommend that more qualitative researchers ask questions such as “Who is/ are the main knowledge producer(s) in this research project?” “What are the researchers’ and participants’ roles in the field and during the data analysis?” and “How does this research relate and inform practice?” These questions and reflections are ultimately (e)pistemological questions that could assist a researcher in designing a study that reflects and supports the researcher’s (e)pistemological stance and theoretical perspective. (Koro-Ljungberg et al., 2009, p. 694)

I asked the above three questions of myself and came up with the following answers:

The main knowledge producers in my research project are my participants.

During the fieldwork, the participants’ role is to either provide me with factual information about their current situation or engage in a reflective process to respond to questions concerning their wishes and worries and the changes they desired for their children’s long-term future. My role during the field work is to seek information from the participants through appropriate questioning, and use probing where necessary to assist the participants in engaging in a reflective process. During the data analysis, the participants have no role to play and my role is to accurately dissect the data to produce findings that reflected the participants’ accounts in an authentic way and use those findings to generate meaningful outcomes.
This research relates to and informs practice through providing an insight into the lives of people directly affected by the practice and by providing participant-driven recommendations to improve practice.

The above answers clarified that the epistemological stance that best described my approach to this research was constructionism. It was not subjectivism because the meaning was to be constructed through my interaction with my participants and not generated all by myself and which I would then impose on my participants. Similarly, it was also not objectivism as my participants' views and experiences were to play an important part in the knowledge generation process and that knowledge was not just “out there” ready for my participants to share with me independent of their consciousness (other than, of course, some factual information). Given the reflective process my participants needed to go through and my interaction with participants during that process, the notions of construction of knowledge through interaction between human beings and their world embedded in a constructionism paradigm resonated the most with my research approach.

Further, as Sarantakos (2013) explains:

Constructionism focuses on the firm belief that there is in practice neither objective reality nor objective truth. On the contrary, reality is constructed…it follows that the construction of reality is an active process of creating a world. The reality people experience in everyday life is a constructed [emphasis in original] reality – their reality – based on interpretation. (Sarantakos, 2013, pp. 37-38)

The information sought by me from the participants was in essence their interpretation of their reality constructed by their everyday experiences of caring for an adult child with HCN. Therefore, from an ontological perspective, the nature of the reality being studied was constructed reality; and from an epistemological perspective, the reality was to be studied using an interactional approach of co-constructing knowledge and generating meaning. Thus, constructionism reflected both my epistemological and ontological stances in this study.

5.1.3 Theoretical perspective

The term “theory” can be defined in a number of different ways. “In a formal sense, social scientists usually define theory as a system of logical statements or propositions
that explain the relationship between two or more objects, concepts, phenomena, or characteristics of humans – what are sometimes called variables” (Berg & Lune, 2012, p. 20). When defined as such, the role of theory becomes providing a conceptual framework for the study. In that sense, the discussion in Chapter 3 surrounding the triangulation of rights, choice, and support provides a rights based theoretical and conceptual framework for my study. The concepts of rights, choice, and support are crucial elements that, individually and collectively, have a significant influence on people’s lives in the modern world. In the context of my study, as explained in Chapter 3, the theory suggests that disabled adults with HCN and their families have a right to support and also have a right to choose the type of support they receive. This research looks at the existing practice implications of this theory and seeks to understand from the parents’ perspectives how the theory and practice can be better aligned for securing a better future for their loved ones.

Theory is also defined as “a way of interpreting events and provide a framework or means by which to make sense of the world in which we live and practise” (Carey, 2012, p. 69). When so defined, theory provides us a perspective – a way of seeing the world. The literature suggests that the three broad theoretical perspectives are positivism, interpretivism and critical theory (Carey, 2012; Crotty, 1998). Again, by resorting to the answers that helped me clarify my epistemological position, it became clear that my study aligned closely with an interpretive theoretical perspective.

As discussed earlier, according to the constructionist epistemology, reality is not discovered but constructed through an interactive process. Sarantakos (2013) proposes that “the key process that facilitates construction and reconstruction is interpretation” (p. 40); and it is interpretation that is the central element of an interpretivist theoretical framework. Interpretive theory is concerned with “how people interpret and understand their direct experiences in the social world” (Carey, 2012, pp. 74-75). My study was concerned with how the parent participants interpreted and understood their experiences of raising an adult child with HCN and their experiences with both formal and informal support. Thus, gaining a better understanding of the parents’ interpretations of their situation was a central component of the study. It is suggested that an interpretivist theoretical perspective aligns closely with constructionism as an epistemology (Carey, 2012) and qualitative research as a methodology (Sarantakos, 2013).
5.1.4 Methodology

According to Crotty (1998), justification for choice of methods or methodology is guided by the research question and/or the aim of the research. “It is obvious enough that we need a process capable of fulfilling those purposes and answering that question” (Crotty, 1998, p. 2). Whilst influenced by my interpretivist theoretical perspective, the research aim and the research questions described in Chapter 1 primarily guided my choice of research methodology and methods.

Two most popular and widely used methodological approaches are qualitative and quantitative research. Another approach, mixed-methods research (MMR), has gained popularity over the last couple of decades. This basically assimilates both qualitative and quantitative approaches in the same research project. Some common contrasts between quantitative and qualitative research identified by Bryman (2012) suggest that a qualitative approach is more suited when the researcher is concerned with words (rather than numbers), the point of view of the participants (rather than the researcher’s) and in gaining rich deep data (rather than hard, reliable data). This quality of qualitative research to produce rich data is also endorsed by several other authors. Qualitative research generates data that are “detailed, rich and complex” (Ormston, Spencer, Barnard, & Snape, 2014, p. 4); and that are “culturally specific and contextually rich” (Mack, Woodsong, MacQueen, Guest, & Namey, 2005, p. vi). This study was primarily concerned with gaining rich information from the parents on their views and perspectives concerning the future needs of their adult children with HCN rather than gaining factual information from a large number of parents and then trying to generalise findings for a larger population. Therefore, a qualitative design was chosen for this study to favour depth and richness of data over generalisability.

“Clearly, certain experiences cannot be meaningfully expressed by numbers…The meaning that we give to events and things comes from their qualities. To understand our lives, we need qualitative research” (Berg & Lune, 2012, p. 3). I embarked upon my research journey to gain a better understanding of the lives of the parents of adults with HCN and a qualitative approach was more suited for gaining such an understanding. In addition, according to Padgett (2008), a qualitative approach is better suited for studies dealing with a topic of “sensitivity and emotional depth” (p. 15), and those concerned with capturing the “lived experience from the perspectives of those who live it and create meaning from it” (p. 16). The overarching theme of this study required the
participants to think about a situation when they were no longer alive and thus made it a topic of great sensitivity and emotional depth. The study also sought to explore the influence of current and future formal and informal support structures on their wishes and worries concerning their children’s future and hence was concerned with their lived experiences.

Another important aspect of a qualitative research is that it adopts a naturalistic and interpretative approach where the researchers “study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Sarantakos, 2013, p. 37). Thus, it allows a researcher to observe, describe, or interpret a research issue in a way that the participants experience it or make sense of it (Bazeley, 2013; Ormston et al., 2014). On similar lines, Carey proposes that in social research a qualitative approach can help “broaden our understanding of the complexity of service user, carer or wider family related needs” (Carey, 2012, p. 9). To achieve my aim of being able to produce some robust recommendations for design and delivery of support services that would work for these families, broadening my understanding of their situation as service users and wider family needs that Carey alludes to above was a crucial component of my study.

Finally, a qualitative approach also assists the research participants in providing more meaningful responses.

One advantage of qualitative methods in exploratory research is that use of open-ended questions and probing gives participants the opportunity to respond in their own words, rather than forcing them to choose from fixed responses, as quantitative methods do. Open-ended questions have the ability to evoke responses that are:

- meaningful and culturally salient to the participant
- unanticipated by the researcher
- rich and explanatory in nature. (Mack et al., 2005, p. 4)

Thus, a qualitative research “provides information about the ‘human’ side of an issue” (Mack et al., 2005, p. 1). As mentioned earlier, the voice of the parents of the adults with HCN is often not heard and hence, bringing to fore the human side of this issue, and gaining an understanding of the sense the parents make of their situation was vital and a
qualitative approach aptly facilitates this. To ensure the congruence between my chosen methodology and the methods, as described in the next section of this chapter, I adopted methods of sampling, data collection and data analysis that align well with qualitative methodology.

5.2 Methods

Whilst research methodology is a broad strategy or action plan for conducting the research, methods are “the techniques or procedures used to gather and analyse data” (Crotty, 1998, p. 3). Methods are the tools a researcher uses to put the methodological action plan in action. Thus, methods facilitate the practical activities conducted during research such as sampling, data collection and data analysis (Carter & Little, 2007). This section describes these key research activities in this study including an explanation of the specific methods used during each stage of the process.

5.2.1 Sampling

A sample is the part of the target population that a researcher studies and sampling is the process that the researcher follows to select that sample. As highlighted by the recruitment strategy discussed later in this chapter, the primary sampling technique used for the study was purposive sampling. Qualitative researchers tend to prefer purposive sampling for their work as opposed to the probability sampling preferred by quantitative researchers (Bryman, 2012; Mack et al., 2005). “In this technique the researchers purposely choose subjects who, in their opinion, are relevant to the project [emphasis in original]” (Sarantakos, 2013, p. 177) and thus, it “places the investigator’s research questions at the heart of the sampling considerations” (Bryman, 2012, p. 416).

The participants were therefore selected using the following sampling criteria:

- parent/s of an adult with HCN aged 18 years or over;
- looking after their disabled child at home (i.e. the child should not be living full-time in a residential facility); and
- living in Delhi or Auckland at the time of the interview.

The reason for not including the parents of those children who were already living in a residential home was that the circumstances of those parents would be significantly different to those who were still looking after their adult children at home. While the question of their children’s long-term well-being might still be of a significant concern
for them, their wishes and worries were likely to be influenced by the factors significantly different from those parents caring for their adult children themselves at home.

Chapter 1 described in detail why India and New Zealand were chosen for conducting this research. Within these countries, the cities of Delhi and Auckland were chosen as the study sites as both are urban centres of the respective countries; and they both also have universities that are part of the Universitas 21 (U21) network, potentially offering opportunities for collaboration during and after the research. The strategy adopted allowed doing sampling both for heterogeneity – i.e., countries with varying levels of parental access to formal and informal supports – and homogeneity, i.e., urban areas of the respective countries.

It was also decided to use snowball sampling if sufficient participants were not found. Snowball sampling, also referred to as chain referral sampling (Mack et al., 2005) involves requesting initial participants to recommend other participants (Sarantakos, 2013) and is often used for recruiting hard-to-reach participants (Berg & Lune, 2012). This was, however, not required for selecting the parent participants as adequate numbers volunteered to participate.

**Recruitment Strategy**

**Recruitment of Auckland participants**

An invitation to participate in the study was prepared, in the form of an advertisement, covering brief introduction to the researcher, the purpose of the study, the sampling criteria, and the contact details of the researcher. The Complex Carers Group (CCG), an organisation supporting the carers of people with HCN was approached to circulate the advertisement to its members. The CCG emailed the advertisement to its members and also posted it on their Facebook page. A parent member of the CCG subsequently posted my study invitation on the Facebook page of Angelman Network; and another parent circulated the invitation through the e-newsletter of another organisation called Disability Connect.

The parents who contacted me expressing an interest in participating in my study were then sent copies of the Participant Information Sheet (PIS) and the Informed Consent (IC) form if they met the selection criteria described earlier. Having read the PIS, those parents who gave consent to participate in the study were then recruited on first-come,
first-served basis. A suitable time and place to conduct the interviews were agreed as per the parents’ convenience. In most cases, the interviews were conducted at the parents’ homes as it suited them better.

**Recruitment of Delhi participants**

An invitation (in both English and Hindi) following a similar format to the one for Auckland participants was prepared for Delhi participants. These invitations also included my local contact number in Delhi. Initially, the invitations were circulated to parent members of two disability organisations: the Society for Child Development (SFCD) and the National Association for the Blind (NAB). Since a majority of the Hindi-speaking parents did not have access to email, hard copies of the Hindi versions of the advertisement, PIS and IC were sent to the parents through their children who attended the activities at these organisations.

Unlike Auckland parents who contacted me on their own, many parents in Delhi needed a follow-up phone call from the staff of these organisations reminding them to read my advertisement and PIS and then contact me if they were interested. In some cases, the agency staff took the participants’ permission to pass on their contact details to me and informed them that I might contact them directly. In either case, once a contact was established, those parents who agreed to participate in the study were then recruited on a first-come, first-served basis.

According to Berg and Lune, “In some instances, purposive samples are selected after field investigations on some group in order to ensure that certain types of individuals or persons displaying certain attributes are included in the study” (Berg & Lune, 2012, p. 52). Most of the parent participants recruited through the first two organisations belonged to lower socio-economic backgrounds. Hence, to get a mix of parents from other socio-economic backgrounds, I approached two more disability organisations in Delhi with a request to circulate my advertisement. With the support of these organisations I managed to recruit some parents from middle and higher-income groups. A suitable time and place were agreed as per the parents’ convenience to conduct the interviews. In most cases, the interviews were conducted in a private room at the premises of the organisation that their child attended. Some interviews were conducted at parents’ own homes.
It should be noted that all the versions of the advertisements, PIS, and IC forms were approved by the University of Auckland Human Participants Ethics Committee (UAHPEC) and included the ethics approval reference number as a footnote. A copy of the UAHPEC ethics approval letter is attached as Appendix 1.

**Sample size**

There does not seem to be a consensus around an ideal sample size. According to David and Sutton (2004), the sample size should be a minimum of 30, whereas Gerson and Horowitz (cited in Bryman, 2012) suggest that “fewer than 60 interviews cannot support convincing conclusions and more than 150 produce too much material to analyse effectively and expeditiously” (p. 425). Bryman (2012), however, argues that a smaller sample can be justified if the researcher feels that theoretical saturation has been achieved; that is, no more new or relevant data seem to be emerging regarding a category. As such, the size of a sample that supports convincing conclusions varies from situation to situation and “qualitative researchers have to recognise that they are engaged in a delicate balancing act” (Bryman, 2012, p. 425). Thus, the sample should not be too small or too large. As aptly summarised by Sarantakos, “the sample must be ‘as large as necessary, and as small as possible’” (Sarantakos, 2013, p. 183).

For this study, interviewing approximately 15 participants (up to a maximum of 20) from each city was considered appropriate to facilitate gathering sufficient rich data from the parents while still keeping the scope of the study manageable. Eventually, a total of 32 parent interviews were conducted – 14 in Auckland and 18 in Delhi. Table 1 in Chapter 6 provides the detailed demographics of the parent participants.

In Auckland, I had already conducted 14 parent interviews prior to going to India for my field work and the plan was to conduct more interviews upon my return. However, once all the parent interviews were transcribed and the initial coding of the transcripts was done, no new information was coming in the later interviews of Auckland parents and hence it was decided, in consultation with my supervisors, not to conduct any more interviews as data saturation had been achieved.

**Recruitment of key informants**

It was considered that, in addition to interviewing parents in the two geographical contexts, interviewing key informants would be valuable particularly for developing
robust recommendations from a service delivery perspective. Accordingly, permission was obtained from the ethics committee to interview key informants from both cities.

In Auckland, key informants were chosen using my professional networks, whereas, in Delhi the professionals were chosen based on their area of expertise within disability sector in consultation with the Director of the Society for the Child Development. In Delhi, two key informants originally approached by me were not available for interview and hence snowball sampling was used to replace them by using the recommendations of the other key informant participants. All the key informants from both the cities possessed a number of years’ experience in the disability sector and included government officers, academics, service providers, and the heads of the community organisations. A total of 13 key informants were interviewed – six in Auckland and seven in Delhi. A separate PIS and IC form were designed for the key informants. These were emailed directly to the key informants once the ethics approval was granted. A suitable time and place were then agreed as per the participants’ convenience to conduct the interviews. In most cases, the interviews were conducted at the key informants’ offices.

A number of parent participants as well as the key informants expressed an interest in receiving the summary of findings. After successful completion of the study, an executive summary of the findings will be distributed via post or email to all the interested participants.

5.2.2 Data collection

In an interpretivist/ constructivist qualitative study, use of personal interviews is often the main method of data collection (Koro-Ljungberg et al., 2009). Also known as qualitative interviews (Sarantakos, 2013) or in-depth interviews (Mack et al., 2005), individual interviews with the participants are preferred by qualitative researchers for some of its inherently useful characteristics. Sarantakos (2013) has compiled a list of nine such useful characteristics of qualitative interviews, one of which he has named “Primacy of the respondent.” According to him, “the respondents are experts who provide valuable information. They are as important as the researcher and not just a source of data” (Sarantakos, 2013, p. 280). This overarching notion of participant-as-the-expert inherent to qualitative interviews is vital for accurate and authentic
interpretation of their life experiences so that the subsequent process of construction of
meanings, ideas, or solutions becomes more relevant to the participants’ real lives.

Further, as suggested by Mack et al. (2005), “in-depth interviews are optimal for
collecting data on individuals’ personal histories, perspectives, and experiences,
particularly when sensitive topics are being explored” (p. 2); and “they are very
effective in giving a human face to research problems” (p. 29). My primary research
questions concerned capturing the participants’ views and perspectives and the research
topic itself was of a highly sensitive nature. Hence, in-depth interviews were considered
as the most appropriate method of data collection for this study. In addition, in-depth
interviews are also considered to offer a rewarding experience to the participants in the
sense that they offer them “the opportunity to express themselves in a way ordinary life
rarely affords them” (Mack et al., 2005, p. 29). Accordingly, it was decided to conduct
face-to-face in-depth interviews with the research participants.

There are three main types of interviews: structured, unstructured, and semi-structured
(Bryman, 2012; Sarantakos, 2013). As the name suggests, structured interviews demand
a strict adherence to the order and wording of the questions from one interview to the
next. In an unstructured interview, a number of open-ended questions are used, the order
of which and the way the questions are posed can be changed as necessary. Unlike a
structured interview, the flow of an unstructured interview can be significantly different
from one interview to another.

A semi-structured interview has elements of both a structured and an unstructured
interview and is often a preferred method of interviewing for qualitative and feminist
researchers (Sarantakos, 2013). For this study, it was decided to conduct semi-structured
interviews as, unlike a structured interview, it focuses more on the viewpoint of the
participant as opposed to the researcher’s agenda; it allows for flexibility for the
participants to tell their stories more naturally; and provides for more rich and detailed
responses (Bryman, 2012). Further, unlike an unstructured interview, a semi-structured
interview enables the researcher to guide the interview process in such a way that all the
key questions that are considered important to the research are covered (without
adhering to any specific order) during the course of the interview.

It was also decided to record all the interviews using a digital audio recorder. There are a
number of advantages of recording an interview with the most important being “it helps
to correct the natural limitations of our memories and of the intuitive glosses that we might place on what people say in interviews” (Heritage, cited in Bryman, 2012, p. 482). Since, all the interviews were of significantly long duration, it was really helpful to have them audio recorded to accurately and completely capture what each participant said and with what emotions.

**Interview schedule**

An interview schedule allows coverage of specific questions and at the same time offers enough flexibility to probe the participants to elaborate on key ideas and speak more widely on any points of interest (Denscombe, 2010; Grinnell & Unrau, 2011).

In a semi-structured interview:

The researcher has a list of questions or fairly specific topics to be covered, often referred to as an interview guide, but the interviewee has a great deal of leeway in how to reply. Questions may not follow on exactly in the way outlined on the schedule. Questions that are not included in the guide may be asked as the interviewer picks up on things said by interviewees. But, by and large, all the questions will be asked and a similar wording will be used from interviewee to interviewee. (Bryman, 2012, p. 471)

In preparing the interview schedule (see Appendix 2), I considered the recommended good practice principles such as using open-ended and non-leading questions (Yeo et al., 2014); and keeping the questions relevant to the broad research question and using a language appropriate to the participants (Bryman, 2012).

To collect demographic information and gain a better understanding of the participants’ current support situation, a questionnaire consisting primarily of close-ended questions was prepared and was administered by me prior to using the interview schedule. The questionnaire focused on the existing sources of support (both formal and informal support) available to the parents in the following areas related to their disabled children’s care:

- home and personal care;
- mental and physical health;
- social and vocational;
- financial support and management;
• decision making; and
• support for them as a parent.

These areas broadly cover the various aspects listed under the “My needs” section of the Supported Self-Assessment tool developed by the MoH as one of the initiatives under the New Model (Ministry of Health, 2016b). This tool also covers family’s access to both formal and informal support.

It is recommended that the interview schedule is tested prior to using it for the interviews. According to Berg and Lune (2012), testing the interview schedule is a two-step process. First, it is important to get it checked by a subject-matter expert or other researchers to ensure the wording of the questions is appropriate and does not include personal bias or emotionally loaded words. This first level of checking was done by my supervisors giving me feedback on the interview schedule.

The second step involves doing practice interviews to assess “how effectively the interview will work and whether you will obtain the information you seek” (Berg & Lune, 2012, p. 127). As part of this step, pilot testing of the interview schedule was done with participants from both cities.

**Pilot testing**

To ensure that the broad questions used in the schedule were relevant for the participants and that they answered the key research questions, it was decided to conduct pilot interviews in both the cities and collect feedback on the questions and the interview process from the participants. One pilot interview was conducted in Auckland and two were conducted in Delhi – one in Hindi and one in English.

To ensure the format of the interviews was as similar as possible to the other real interviews to follow, all the three participants were given a copy of the PIS and asked to sign the IC form. In all cases, I also offered the participants grocery vouchers to thank them for their time.

At the end of the interviews, the parent participants were requested to provide their feedback using the following questions as guidelines:

• Was there anything that I did not ask that was important?
• Was there anything that I asked that was not relevant or should have been asked differently?
• Is there any feedback you can give me to help me make future participants more comfortable?
• Is there anything about me (e.g., being a student, Indian, disability professional) that you think might have influenced what you shared with me?
• Is there any other feedback you can give me to make the findings of this research more robust and meaningful?

Both the participants from Delhi chose to provide verbal feedback straight after the interview. Both the parents mentioned that the interview covered everything that they expected and provided positive feedback on my interview style and how comfortable I made them feel during the interview. They did not have any suggestions for what I needed to do differently.

The Auckland parent who took part in the pilot chose to provide the feedback by email at a later time so I left the list of feedback questions with her at the end of the interview. The feedback received from her had the following suggestions:

• Ask more detailed questions about the current support needs and how those needs are met.
• It is hard to think of future wishes and worries in general so it is better if the parents are asked to talk about their wishes and worries in individual areas such as home and personal care, mental and physical health, social needs and so on.

With regard to the first feedback, since my primary research questions were more future focused, I felt that the information that I was seeking on their current support network was sufficient for the purpose of providing me with background information on their existing support. Hence, a need for any further probe into the current situation was not felt necessary. In response to the second feedback, no changes were required to the interview schedule itself; however, I ensured that, during the interviews I used appropriate probes to encourage parents to think of different support areas when responding to my open-ended questions.

**Subsequent changes to the interview schedule**

After the pilot testing phase when the interviews began, I made field notes at the end of each interview to record the key points raised by the participants and also as a tool of reflection on the interview process. After the first couple of interviews with Auckland
parents, I noticed that the final question concerning the three most important changes that would help parents die peacefully elicited an emotional response from the parents as it took them by surprise. I felt a need to make some changes to how I approached that final question and accordingly made the following two changes:

1. I decided to give parents a chance to look at the final set of four sub-questions concerning the three most important things and take 5-10 minutes to think about the answers before continuing with the interview; and

2. I moved the most sensitive sub-question, “Three most important changes that would help you die peacefully” up the order rather than leaving it to the end.

These changes allowed parents during the subsequent interviews to have some time to gather their thoughts around what they considered to be the three most important things and it also made them feel more at ease in answering that question and reduced some of the emotional sensitivity surrounding that question.

**Interview process**

The success of any interview depends upon the relationship the researcher manages to establish with the participant/s on the day, particularly when they are first meeting each other on the day of the interview. A couple of factors that are really crucial to establishment of this relationship are the participant’s perception of the researcher’s reliability and the respect shown by the researcher towards the participant, including his or her specific culture (Mack et al., 2005). In this regard, I ensured that I always reached the place of the interview on time; I was always dressed appropriately; I switched my mobile phone off; and I removed my shoes at the door particularly when the interviews were conducted at the participants’ homes.

I began each interview by thanking the parents for agreeing to participate in my study and then briefly introduced myself. I shared with the participants my experience in the disability sector in both India and New Zealand including various roles that I have had during my working tenure. I felt that talking about my experience in the field provided parents with an assurance that they were talking to someone who understood what they were talking about. Many parents even commented at the end of the interview that they felt comfortable talking to me in detail about some of the issues they faced with the formal support system because I had good understanding of how the system works.

Further, out of 18 parent interviews in Delhi, 14 were conducted in Hindi. The
challenges that are usually faced by the researchers in conducting an interview in another language where they need a translator to be present were not faced in this case as I am a fluent speaker of Hindi. My ability to converse with the parents in Hindi made them feel more comfortable during the interview.

After the introductions, I ran through the key points of the PIS with each participant and then asked them to sign the IC form, if they had not already done so. Where required, I provided further explanation to the parents on each point listed in the IC form. I made particular emphasis on the points that the interviews would be audio recorded and that they were free to ask me to stop the recorder at any time.

All the interviews began with the researcher-administered questionnaire to collect demographic data and then the formal interview followed using the questions in the interview schedule. Wherever possible, I tried to follow a similar sequence when asking the broad questions from the schedule. However, if the flow of discussion took a different direction, the sequence was changed. For example, when talking about wishes or worries, if the parents started talking about the attitude of the society, they were asked to elaborate upon that at that time rather than asking about it separately later on.

Kvale and Brinkman have proposed two metaphors for the interviewers – a miner and a traveller.

The miner metaphor sees the interview as in interaction which accesses and acquires the participant’s pre-existing knowledge or views … traveller metaphor sees knowledge as something which does not already exist, but which is created and negotiated in the interview, with both interviewee and researcher actively participating and interpreting. (Kvale & Brinkman, cited in Yeo et al., 2014, pp. 178-179)

Having a specific set of open-ended questions as part of my interview schedule assisted in ensuring that all the key information was collected from the participants and probing was used for gathering additional information where necessary. Thus, it can be said that I took the stance of a “traveller” in my study as I did play a part in creating the knowledge during the interviews by probing for more information than what the participants had initially shared with me.
Probes are questions or neutral statements that encourage the respondents to extend or amplify a partial, irrelevant or inaccurate response, and/or to stimulate and assist them to answer a question, without affecting the direction of their thinking and without causing bias or distortion. Probes are employed in interviews where open discussion is allowed, such as intense interviewing. (Sarantakos, 2013, p. 289)

Based on the feedback received during the pilot testing, I also ensured that I prompted the participants to talk about their wishes and worries concerning all aspects of their children’s support needs. While asking the questions or probing the participants for further information, I ensured that I posed my questions in a neutral manner, listened attentively, neither led participants to give a particular response nor provided an approval or disapproval of their response based on my personal views or beliefs.

Even when an interview is being recorded the interviewer needs to be attentive to what the interviewee says and pay attention to body language and signs of distress, if any. “An ethically sensitive interviewer will not want to place undue pressure on the person he or she is talking to and will need to be prepared to cut short that line of questioning if it is clearly a source of concern” (Bryman, 2012, pp. 478-479). During all the interviews I was also paying special attention to the body language, tone of voice and facial expressions of the participants. If parents were getting emotional or needed time to gather their thoughts or compose themselves, I ensured that I gave them sufficient time to do so. Where felt necessary, I also offered parents an opportunity to take a break before continuing with the interview. Further, often during the interviews there were other disturbances such as the phone or the door bell ringing or the pets needing attention. I ensured that the recorder was paused during the time when the parents were attending to such other things.

I finished each interview by offering the participants an opportunity to share any further information that was not already covered and also to ask me any questions. Once an interview was formally over, if we still continued to talk, I kept the practice of keeping the recorder on for little longer just in case the parent shared something really important. As pointed out by Hammersley and Atkinson (as cited in Bryman, 2012), “such ‘unsolicited accounts’ can often be the source of revealing information or views” (p. 470). On a couple of occasions, I felt that the parents were sharing some relevant
information and hence I asked their permission if I could use those comments as part of the interview and they granted permission to do so.

Finally, before leaving the interview premises, I thanked the participants again and as mentioned in the PIS, I offered each participant a grocery voucher (NZ$30 to Auckland parents, and INR₹1,500 to Delhi parents) as a token of appreciation for their time.

Overall, conducting in-depth parent interviews was a very enriching process and I was humbled by the parents’ willingness to share their life stories with me in such an open and honest manner. It was indeed an honour and a privilege to hear those stories and I learnt a lot from my parent participants. I am also aware of the responsibility that this honour brings – a responsibility to make sure that those stories are presented in a meaningful way and that they are heard by those who need to hear them so that those stories can have the outcomes desired by the parents and their adult children with HCN.

**Key informant interviews**

All the key informant interviews were also conducted using a semi-structured interview schedule with questions similar to those asked of the parents except for the questions regarding wishes and worries. Since, all key informants in Delhi were fluent English speakers, it was not necessary to prepare a Hindi version of the interview schedule.

One key informant interview in New Zealand was conducted using Skype as the participant was based outside Auckland and it was not feasible for me to travel to conduct the interview. During the key informant interviews in both countries, I followed a more or less similar process and the level of care and diligence to the one described above for parent interviews. Unlike the parent participants, the key informants were not offered any grocery vouchers.

Overall, conducting key informant interviews was also a very enriching experience for me and it was pleasing to see the commitment amongst the professionals in both the countries to make a positive difference in the lives of people affected by their work.

**Agency visits in Delhi, India**

During the field work in Delhi, I also visited eight agencies including schools, vocational centres and residential facilities for disabled people. Conducting these visits helped me to get an insight into how these agencies operate, observe first-hand the creative work done by some of the agencies, and also a better appreciation of the
challenges faced by them in carrying out their work. These agency visits were not part of formal data collection.

The following section discusses the process of data analysis.

5.2.3 Data analysis

The process of data analysis involves “a close engagement with one’s [data], and the illumination of their meaning and significance through insightful and technically sophisticated work” (Antaki, Billing, Edwards, & Potter, cited in Bazeley, 2013, p. 4).

There are numerous methods of data analysis but the most common types used by qualitative researchers are thematic analysis, grounded theory, and narrative analysis (Floersch, Longhofer, Kranke, & Townsend, 2010; Koro-Ljungberg et al., 2009). Each of these analytical methods serves a different purpose and therefore, the choice of analysis type depends upon the research question. Analysis can have “description”, “explanation”, or “theory development” as its ultimate aim (Spencer, Ritchie, Ormston, O’Connor, & Barnard, 2014). In this study, the aim of the analysis was to describe parents’ wishes and worries concerning their children’s future and their experiences with formal and informal support including an explanation of why they considered certain aspects of supports more valuable than others in the context of their lives. Theory development was not one of the aims of my study or data analysis. Flick (as cited in Padgett, 2008) asserts that “requiring theory development constitutes an excessive and unrealistic burden for many studies, especially graduate thesis and dissertations” (p. 151). Carey (2012) concurs with this view and proposes that research students are not expected to create a new theory. Thematic analysis was chosen as the method of data analysis for this study as it aligned the best with my research aim and the research questions that I needed to answer.

Thematic analysis is one of the most common approaches to qualitative data analysis and allows the categorisation of data into themes and sub-themes. It involves “discovering, interpreting and reporting patterns and clusters of meaning within the data” (Spencer et al., 2014, p. 271); and in doing so, it “move[s] beyond counting explicit words or phrases and focus[es] on identifying and describing both implicit and explicit ideas within the data, that is, themes” (Guest, MacQueen, & Namey, 2012, p. 11).
Thematic analysis in social studies concerns analysing research data to understand social issues from the participants’ perspectives and then apply that understanding to design solutions to resolve those issues/problems. In this study, such an approach was considered useful for identifying the key themes in the wishes and worries of the parents and in the type of support (formal and informal) the parents valued as being significant for the future of their adult children with HCN. Thematic analysis of the transcripts was conducted to generate meaning from the data. Before more detail on the process of analysis is provided, a brief description of the transcription process follows.

**Transcription**

Bailey (2008) argues that transcribing – converting the data from an audio (or video) format to a written format – is an interpretive process in itself and therefore it essentially becomes the first step of data analysis. And being an interpretive process, a transcript is always going to remain the transcriber’s interpretation of what is conveyed by the participant at the time of the interview.

Transcripts cannot convey the same meanings, emotions, reactions, humor, or hesitations that can be heard, seen, and experienced in the real-time... Even inserting comments for ‘laughter’ or ‘subject hesitates’ in brackets in the text is only a small representation of what could have been a significant moment in the research. Thus, transcripts are always acknowledged as a partial and imperfect data source, though there are ways to minimize errors. (Cope, 2009, p. 350)

One of the most important ways of minimising the transcription errors that Cope refers to above is to do self-transcription. Barnes (as cited in Bryman, 2012) identified the following advantages of self-transcription:

I chose to transcribe the interviews myself because, whilst it was an arduous and very time-consuming task, it offered great benefits in terms of bringing me closer to the data, and encouraging me to start to identify key themes, and to become aware of similarities and differences between different participants’ accounts. (Bryman, 2012, p. 486)

I transcribed all the parent and key informant interviews. It was a very time-consuming process to transcribe 45 interviews (32 parent interviews and 13 key informant interviews). Despite the time taken for transcribing, I felt that the process of self-transcription certainly helped me relate more to the data. The other advantage I felt of
doing the self-transcription was that listening again to the tone in which a certain message was given helped me to understand how important or otherwise that point was for the participant. When someone else does the transcription, it is not possible to get that richness of emotions and feelings behind each message that one can experience whilst doing self-transcription. Cope (2009) identifies this possibility of recalling and accurately capturing the emotions and feelings as one of the key advantages of self-transcription and suggests that “all of these contribute to more accurate texts that are ‘thicker’ with description and supporting information” (Cope, 2009, p. 352). Further, self-transcription also helps early identification of emerging themes and ideas that can be useful later during the analysis stage. After the few initial transcripts, I started making a note in a separate document of the key messages or themes that surfaced as the transcription progressed.

Interviews conducted in Hindi were translated into English simultaneously at the time of transcribing. A similar process was followed for those Delhi interviews that were primarily conducted in English but where the participants had, at times, used some Hindi sentences. I was conscious of the challenges associated with the accurate translation as often the meanings of the words change when applied in different linguistic or cultural context. Often, “the original language is needed to convey nuance of the text” (Bazeley, 2007, p. 46) as translation “adds an additional layer of interpretation to the transcribing process” (Bailey, 2008, p. 129). In consideration of this, where appropriate, the corresponding Hindi words or phrases were written in parentheses next to the English translation to capture the original intended meaning. Nikander (2008) argues that there is not enough supportive literature around translation and the qualitative researchers are often “left to cope and come up with their own solutions” (p. 226).

Each transcript was saved electronically using the participant’s pseudonym and then protected with a password.

Key informants were offered an opportunity through the consent form to view and edit the transcripts but none of the key informants opted to do so. However, it was decided not to share the transcripts with the parent participants as it is suggested that reading transcripts often evoke emotions that cause discomfort to the participants (Mero-Jaffe,
Discussing a number of other advantages and disadvantages of sharing transcripts with the participants, Mero-Jaffe (2011) argued that:

Despite the inherent advantages of transferring transcripts to interviewees, such as enhancing the validity of the transcript, and receiving clarifications and statements that enrich what was said in the interview … the disadvantages to the research study create doubt as to the value of transferring transcripts to the interviewees in qualitative research. (Mero-Jaffe, 2011, pp. 244-245)

Forbat and Henderson (2005) expressed similar views in suggesting that often the participants find reading the transcripts or “seeing their own words on paper” a very emotionally overwhelming experience, and hence “showing participants transcripts of their own talk on sensitive or delicate matters is a component of research that warrants consideration” (Forbat & Henderson, 2005, p. 1117). Thus, given the sensitive nature of my research topic it was decided not to share the transcripts with the parent participants.

**Coding**

Thematic analysis involves identifying patterns or themes in the data. According to Sarantakos (2013), a theme is “a set of categories that share the same or similar meanings” (p. 379) and coding is “a procedure that helps to create categories” (p. 380). NVivo™, qualitative data analysis software, was used to facilitate the coding process and for identifying the key themes emerging from the data.

There are three main types of coding: Axial coding – codes based on pre-identified themes and concepts that are often related to the research question; In-vivo coding – codes based on the words or phrases used by the participants in the available data; and Open coding – codes that a researcher starts identifying based on the common patterns or a single unique idea that emerges from the transcripts (Cope, 2009). All three types of coding were used in this study.

First, all the transcripts were uploaded to NVivo™ under four different folders namely, Auckland parents, Delhi parents, Auckland key informants, and Delhi key informants. NVivo™ makes it possible to auto-code data from multiple documents using the Heading Styles feature of Microsoft Office. So after uploading all the transcripts to NVivo™, they were first auto-coded based on the broad questions used in the interview schedule. It is an acceptable practice to first code the transcripts based on the interview questions (Mack et al., 2005). The auto-coding based on the questions enabled collecting
the responses of all the participants to a particular question in a single place and this in turn, made the subsequent analysis process much more manageable.

Each auto-coded question was then reviewed line by line to identify the emerging key themes based on the participants’ responses. First, axial coding was used to categorise the responses within each question based on the support areas. For example, when reviewing the question on parents’ wishes, the first layer of codes included – wishes related to home and personal care, mental and physical health, social and vocational life, and so on. Then, the process of inductive coding, i.e., developing codes from the data began by first creating the emerging key themes as parent nodes under the Nodes section of NVivo™. Each parent node was then further assigned various child nodes (sub-themes) and many child nodes were also assigned grandchild nodes (sub-themes within sub-themes) to capture the depth of data within each broad theme.

Both in-vivo coding and open coding were used in creating the coding structure. Some in-vivo codes were created based on the information provided by parents – for example, the term “abuse” was used frequently by the parents when discussing their worries concerning their children’s future and hence Abuse was created as a node under the question of worries. Similarly, open coding was used when a pattern was emerging in what various participants were saying. For example, a node named Issues with formal support was created under the question of formal support as a number of parents were talking about the issues they faced in either accessing formal support or how that support was delivered. Child nodes were then assigned based on the specific responses of the parents. For example, “Lack of funding” and “Unqualified workforce” became child nodes under “Issues with formal support” as a number of parents referred to these issues. A similar pattern of assigning in-vivo and open codes was used for each of the broad questions asked during the interview.

Coding is an iterative process and hence the code structure often changes through the coding process (Cope, 2009; Sarantakos, 2013). Some codes can be renamed, deleted or realigned as more and more transcripts are coded. “Conceptually and methodologically, the fluidity and ‘messiness’ of coding can, therefore, actually serve as the strengths of the process” (Cope, 2009, p. 354). My initial coding structure had a large number of child and grandchild nodes under each parent node. However, those child nodes that did not have too many references to it from the participants were later on merged with other
child nodes or their immediate parent node. Thus, the overall nodes structure became more meaningful and manageable as the coding progressed.

During the development of my coding structure, I ensured that my focus was not only on the ideas presented by a number of parents because something that only one person said can also be equally as powerful as others and merit a theme of its own. As Patton (as cited in Floersch et al., 2010) explains, “the significance of a theme is not determined by its frequency but by its ‘substantive significance’” (p. 408). Further, to ensure consistency of themes across participant groups, I used a similar overall coding structure but the parent and/or child nodes were modified to appropriately capture the information provided by each group.

Once the coding was completed, to facilitate the next stage of data analysis it was decided to first create a summary of preliminary findings based on the nodes structure. Since there were two sets of participants (parents and key informants) each spread across two sets of locations (Auckland and Delhi), first individual summaries were prepared for each of these four groups. An overarching summary was then prepared using a matrix in an Excel spreadsheet to capture the similarities and differences in what each group of participants conveyed about each broad question. Creating a spreadsheet with information from all the four sets of participants further helped in identifying some key meta-themes – for example, the significance of interplay between formal support and informal support in supporting people with HCN.

A literature control exercise was then undertaken across those meta-themes to situate the findings amongst other relevant studies and literature in general. This literature control exercise also helped in developing useful recommendations. The NVivo™ software was also used during the literature control process and the relevant information from the literature was coded using the nodes structure similar to the one derived during the coding of the transcripts. Finally, the information stored under various nodes created both from parent transcripts and the literature control exercise was collated to make sense of the data and present them in a meaningful way. Key themes and meta-themes that emerged from the data analysis process are identified and discussed in detail in the next two chapters.
5.2.4 Quality measures

A qualitative design was chosen for this study to favour depth and richness of data over generalisability. It is pertinent at this point to expand on this notion of generalisability as it applies to qualitative research because often qualitative studies are criticised for lacking in features such as generalisability, reliability, and validity. “The issue of generalisation in qualitative research – that is, whether a study’s findings can be said to be of relevance beyond the sample and context of the study itself – is both important and much contested” (Lewis, Ritchie, Ormston, & Morrell, 2014, p. 348).

Lewis et al. (2014) found that various writers have expressed different views about generalisation, reliability, and validity and some say that it is not relevant to qualitative research because statistical measures of validity and reliability are inappropriate for a qualitative study. Hence, instead of generalisability, reliability, and validity often the terms used as measures of quality of a qualitative study are “trustworthiness”, “robustness” or “credibility” (Bazeley, 2013; Lewis et al., 2014).

Ormston et al. (2014) propose that achieving the above measures in a qualitative study demands rigour. In this context, one must “strive to conduct research that is well-designed and well-conducted, and to generate well-founded and trustworthy evidence” (Ormston et al., 2014, p. 23). I would briefly touch upon a few processes that I believe have helped me in maintaining the necessary rigour in designing and conducting this study. First, I have made the methodological, epistemological, and theoretical alignments of my study explicit including providing a background to the original research idea. In chapters 2, 3, and 4 I have also provided a detailed account of the literature reviewed and Chapter 3, in particular, discusses the conceptual framework that has guided my study. Secondly, I have ensured that there is congruence between my proposed methodology and the methods chosen at every step of the research process. I have also taken the utmost care during the collection and analysis of data to be as neutral and non-judgemental as possible. Thirdly, under the heading of reflexivity in the ethical considerations section of this chapter, I have made explicit my personal and professional biases, values, and beliefs, and reflected upon the steps taken to minimise the influence of those factors on the research process. Finally, I have endeavoured to ensure that the reporting of data and the conclusions drawn from the data as presented under the chapters to follow are, as far as possible, true and accurate reflections of the
participants’ views and experiences. In this regard, I have often used the direct quotes of the participants to capture the true nuances of their message.

5.3 Ethical considerations

Research ethics help researchers interact with their participants in a manner where the well-being of the participants can be given the utmost importance. Even the research question becomes of secondary importance if research is likely to cause harm to the participants or disrupt their lives in any way (Mack et al., 2005).

Due consideration was given to all the core principles of conducting research with human participants as prescribed by the Human Ethics Committee at the University of Auckland. All the participants were provided a PIS to read and an IC form to sign that clearly addressed all the ethical principles related to the protection of research participants’ privacy and confidentiality, and free and informed consent.

To ensure safe storage, security, destruction and retention of the information, all hard copy data collected were kept in safe custody. All the electronic files containing the list of the participants, interview recordings, and interview transcripts were encrypted and stored securely on a cloud server using strong passwords. All the signed consent forms were also scanned and stored in the computer as a backup and were protected by passwords. To protect the identity of the participants, pseudonyms were used for the participants as well as their children in all the transcripts, and all the electronic files related to each participant were also saved under their pseudonyms. Similar process of using pseudonyms and password protected files was also used for the information related to the key informants. Further, to protect the identity of the other people and agencies that the participants referred to during the interview, no identifying details were recorded in the transcripts.

Since my study also involved conducting fieldwork in India, I also referred to the principles of conducting research as prescribed under the Ethical Guidelines for Social Research in Health developed by the Centre for Enquiry into Health and Allied Themes (Jesani & Barai, 2000). The principles prescribed in the guidelines align with those prescribed by the Human Ethics Committee of the University of Auckland.

Other ethical issues of special consideration for this study include social and cultural sensitivity, minimising harm, and reflexivity.
5.3.1 Social and cultural sensitivity

“Disability does not discriminate. It is a reality for people of all races, genders, ages, social classes, and any other categories” (Yuen, 2003, p. 2). It can happen to anyone at any time. The book *Culture and Disability: Providing Culturally Competent Services* edited by Stone (2005) provides an in-depth account of how disability is viewed and managed across various cultures in several countries.

Since both New Zealand and India are culturally very different to each other, it was crucial that the participants were approached with great respect and sensitivity towards their individual culture. Adopting a universalism approach to cross-cultural research helped me maintain the necessary cultural sensitivity in conducting this study.

According to Berry, Poortinga, Segall, and Dasen (as cited in Hatton et al., 2004), three major stances on cross-cultural research include: absolutism, relativist, and universalism. The absolutism stance assumes that culture plays a small role in how people think because “people are fundamentally the same across all cultures” (Hatton et al., 2004, p. 170); whereas, the relativist stance assumes that “all human experiences are determined by [their unique] culture” (Hatton et al., 2004, p. 171).

The universalism stance, however, takes the middle ground and assumes:

…that basic aspects of human experience are universal, but that a person’s culture will influence how these basic aspects of human experience are displayed. According to this view, we cannot know in advance what aspects of human experience will turn out to be the same across cultures, and what aspects of human experience will be strongly influenced by culture. Careful cross-cultural research is needed to find answers to these questions. (Hatton et al., 2004, p. 171)

Adopting such a universalism stance helped me to be mindful of the cultural influences on the experiences shared by the participants. It also helped me acknowledge that often what is regarded as a dominant culture or the assumptions regarding the culture of a nation (for example, Indian culture) may not influence all the people of that nation in the same way. To put it in the personal context, I am of Indian ethnicity; am a fluent speaker of three Indian languages; and am well aware of general Indian culture and customs. Similarly, I have been living in New Zealand for the 12 years prior to beginning this study and am well acquainted with the Kiwi way of life and basic Māori tikanga
(practices). However, I recognise that, within each culture, people have individual values and beliefs, and hence, without using any presumptions or biases, I was guided by the participants in following appropriate cultural protocols when approaching individual families. In all cases where the interviews were conducted at parents’ homes, I removed my shoes at the door unless otherwise instructed by the participants. Before each interview, the participants were asked if they wanted to begin the process in any particular way such as by saying a prayer. In many cases, where the interviews were conducted at the parents’ home in Delhi, a light snack and/or juice was offered during the interview, which I accepted to be respectful to the participants.

When research is conducted in more than one country, and particularly when a researcher studying in a developed country is conducting research in a developing country, some ethical considerations require the special attention of the researcher. Unite for Sight suggests that, in developing countries, “researchers occupy a position of respect and trust in the community” (Unite for Sight, 2015, module 4). Quoting the Nuffield Council on Bioethics, they further suggest that “it is questionable whether researchers from developed countries are well prepared for the enormous responsibility that this attitude of respect and trust places upon them” (Unite for Sight, 2015, module 4).

Having lived in India for 30 years and having worked for eight of those years in the disability sector, I was well aware of the trust and respect that people place on researchers. I would argue that the kind of trust and respect that Unite for Sight refer to is placed by members of the public in India on all professionals and agencies involved in their (or their children’s) lives either in the health, education or support services areas. For Indian parents, it is very difficult to refuse any request that comes from a school or a centre that their child attends. Since the participants for my study were recruited through the agencies that their disabled child attended, I felt that it was my ethical responsibility to ensure that every participant who agreed to take part in my study was doing so out of his or her own free will and was not either forced to take part or doing it out of a feeling of obligation.

Informed consent is required protection for the participant. Simply having a participant sign a form does not mean that they have given genuine consent. The burden of responsibility is always on the researcher to make sure that his or her
participants are fully informed and therefore may freely choose to participate in the study [emphasis original]. (Unite for Sight, 2015, module 4)

In this regard, before each interview, I checked with the parents that they understood what they were participating in and emphasised that they did not have to take part if they did not wish to. I also offered them an opportunity to ask me any questions before commencing the interview. All the participants told me that they were taking part in my study of their own free will.

Finally, on a few occasions the Auckland parents started to share with me their experiences with an agency that I had worked for in the past. In such cases, I immediately informed the parents that I am an ex-employee of that agency so that they could then decide how much information they share with me about that agency. In all those cases, the parents did not have an issue with me being an ex-employee of that agency and appreciated my honesty in declaring my connections.

5.3.2 Minimising harm

Since the research questions dealt with parental concerns around their children’s future when the parents were no longer alive, on a number of occasions these triggered emotional responses. I found that my ability to listen with empathy and using attentive silence was particularly helpful in comforting and reassuring the participants in such situations.

It is not surprising, if asked to talk about an upsetting or distressing experience, for a participant to become upset or distressed, but this does not mean they do not want to continue. Any unease or embarrassment on the part of the researcher will communicate itself to the participant and could make them reticent about discussing the topic. (Yeo et al., 2014, pp. 203-204)

I remained calm and empathetic during the instances where the parents got a bit emotional and was guided by their facial expressions and body language in deciding how to proceed further. In some cases, it was helpful just to take a short break as it gave the participants enough time to compose themselves before continuing the interview. It is suggested that whilst it is important to listen sympathetically, the researchers should not take on a counselling role (Mack et al., 2005). Therefore, it was decided that where required, the participants would be offered contact details of local professionals/agencies
offering counselling support. However, no participants requested such support nor was a need felt for offering such support to any participant.

Further, as discussed under the data collection section of this chapter, to manage the sensitivity around the question of changes needed that would help the parents die peacefully in relation to their children’s ongoing care, it was decided to change the order in which that question was asked and the parents were also given a break of five minutes prior to answering that question. This change may have helped parents to be more mentally and emotionally prepared to answer that question and thereby minimised the potential emotional harm.

It is important to point out at this stage that, as discussed in Chapter 2, over the years the parents of disabled children become more resilient and self-confident as they learn to deal with various professionals and agencies when advocating for their children. I did observe that resilience in many of my parent participants. Many parents did mention to me that they found it very useful to participate in the study as it gave them an opportunity for self-reflection and thinking about their children’s future. Some also commented that they felt good about being able to share their concerns with someone in an open and relaxed manner. Thus, for many parents the experience of participating in my study was more therapeutic than traumatic.

### 5.3.3 Reflexivity

My motivation for embarking on this research journey came from my own experiences of working in the disability sector. However, as Bazeley explains, this requires caution:

> Your personal goals and preferences in doing research can become a source of bias, however, as they influence not only choices of topic and method, but the very way in which you interact with your participants (or data) and conduct your analysis. (Bazeley, 2013, p. 7)

To minimise the effects of such bias, reflexivity becomes important for qualitative researchers (Ormston et al., 2014). Reflexivity can be defined as the process “in which researchers reflect upon their subjective approach to the world, and take into consideration the implications of the knowledge they produce for social life” (Sarantakos, 2013, p. 280). I would, therefore, like to clarify my role in the research process.
Although I played an interactive role during the field work in assisting the participants to engage in a reflective process and took a more active role during the data analysis process, I was always conscious of the fact that my participants are the main knowledge producers in this research. Hence, I did not take a completely objective or subjective stance but took a position of *empathic neutrality*. It is a position:

…that recognises that research cannot be value free but which advocates that researchers should try to make their assumptions, biases, and values transparent, while striving as far as possible to be neutral and non-judgemental in their approach. In this context, reflexivity in qualitative research is considered particularly important. (Ormston et al., 2014, p. 8)

Thus, I acknowledge that my values, assumptions and biases would have had an impact on the research outcomes, however, as explained below, I endeavoured to be as neutral and non-judgemental as possible in my approach to minimise these effects.

I was aware that I brought with me to this study: my own past history of growing up in India in a Hindu joint family system; my adapted worldview of leading a Kiwi way of life for the past 14 years; and my professional experience of working in the disability sector in both India and New Zealand. Throughout the research process, I encountered numerous occasions where I had to keep these personal and professional experiences in check.

Having lived in a joint family with my uncles, aunties and cousins under the same roof, I had a certain pre-conceived notion of the support that one family unit can get from others. My experience was largely positive where support from and to each other was implied and readily available in all aspects of life. So, during my interviews with the parent participants in Delhi who did live in a joint family, if the parents mentioned that they did not get any support from the other members of the joint family it came to me as a surprise. I had to, however, make sure that I did not show that surprise on my face as otherwise it would have implied that I was judging their family.

My post-graduate studies and the professional work in the disability sector in New Zealand has made me very aware and conscious of the use of language when it comes to disability and disabled people. I have even conducted disability responsibility training where I talk to people about the appropriateness of language. So, during the interviews in Delhi, when the parents or the key informants used terms such as “mentally retarded”
to refer to people with an intellectual disability, or “handicapped” to refer to someone with a physical impairment, I had to not only stop the urge of correcting them but also refrain from showing any disapproval of the language on my face. Unfortunately, in India, even today these terms are commonly used.

As described in the previous chapter, there is a significant difference in the levels of formal support available to disabled people and their families in India and in New Zealand. Therefore, I knew that the families in Auckland were much better supported by the state in all aspects of their children’s needs, including financial support, when compared with the families that I interviewed in Delhi. However, I was careful not to assume that Auckland parents would have fewer worries or that their worries were any less significant than those expressed by the families in Delhi. So, during data collection I had to ensure that I posed the questions around their worries or issues with formal support in a neutral, non-leading way. Similarly, during the data analysis process too, I ensured that I was not specifically looking for any finding that would suggest that one group of parents was better off than the other. I analysed every comment made by every participant based on its own merit and avoided any sort of judgement in reporting those findings.

I consider myself an emotionally strong person so I did not face any particular issues when confronted with emotional responses from the participants. However, at the same time, I had to make sure that my emotional strength did not come across to the participants as indifference towards what they were going through. In such instances, I conveyed to them my understanding and appreciation of their situation in an appropriate manner without being pretentious and gave them time to compose themselves before continuing with their stories.

In addition, throughout my research journey I continued to engage in a reflective learning process through various other means including ongoing supervision with my research supervisors; attending numerous workshops and seminars; presenting at seminars and conferences in both India and New Zealand where I gained useful feedback from the attendees; taking part in thesis presentation competition; and discussing my research, where appropriate, with professionals in the field.
5.4 Limitations and key assumptions

As mentioned at the beginning of this chapter, research studies need to be “realistic with regard both for practical constraints of time and money and for the reality of the research context and setting” (Lewis & Nicholls, 2014, p. 48). These constraints often provide a boundary within which researchers are forced to operate and thereby often create certain limitations as to what researchers would otherwise hope to achieve from their studies.

This study involves the participants living only in urban centres of both countries and as such does not account for the views of the parents living in rural areas. I acknowledge that, for rural parents accessing both the formal services as well as informal support might pose a different set of challenges and, accordingly, influence their wishes and worries concerning their children’s long-term future. Those unique experiences of rural parents are, however, not captured in this study.

Similarly, this study focuses only on the views of the parents of adults with HCN and does not include the other close family members such as siblings who can potentially play a major role in supporting their disabled brother or sister once the parents are no longer alive. I acknowledge that hearing the views of the siblings could have potentially added greater depth to the findings of this study. However, to keep the scope of the study manageable it was not feasible to interview the siblings as well. As discussed further in the discussion chapter, internationally, there are very few studies that capture the views and/or experiences of siblings caring for an adult brother or sister with a disability. Therefore, a future study with a specific focus on the views of the siblings caring for adults with HCN would certainly complement the findings of this study and provide further insight into how these families could be better supported.

Interviewing the disabled children themselves was also beyond the scope of this study. I have, therefore, approached this study with an assumption that all the parent participants have their disabled children’s best interests at heart in how they have responded to the interview questions. I do acknowledge that this assumption means that, in some cases, the responses of the parents may not necessarily reflect the views of their children. Hence, any recommendations made based on the findings of this study to improve the quality of life of their children is also shaded by this assumption.
5.5 Concluding remarks

The first section of this chapter provided a brief background context for this research and discussed the key research elements of epistemology/ontology, theoretical perspective and methodology in relation to this study. This section established that I began this study with an idea that I researched through an extensive review of the literature. The literature review combined with my constructionist epistemological position helped me shape that idea into workable research questions and clarify my research aim. The research questions combined with an interpretivist theoretical perspective, in turn, guided my choice of a qualitative approach as the research methodology. Finally, as described under the second section of the chapter, the qualitative methodological approach guided my selection of the methods such as purposive sampling, semi-structured interviews, and thematic analysis that I used for sampling, data collection, and data analysis, respectively. The third section of the chapter provided an overview of the measures I took to conduct this study in an ethical manner, particularly given the sensitive nature of the topic; and the final section highlighted some limitations and the key assumptions of the study.

The results of my study are now discussed in the next two chapters entitled “Findings” and “Discussion.”
Chapter 6. Findings

The focus of this chapter is on sharing what the parent participants of both countries told me about their wishes and worries concerning their children’s long-term future; and sharing their experiences, views and beliefs concerning various support mechanisms that could potentially assist their adult children with HCN live a good quality of life, particularly when parents are no longer alive. As mentioned in the Methodology chapter, the main knowledge producers in my study are the research participants. Therefore, the key focus of this chapter is on sharing the participants’ stories in their own words (using direct participant quotes) and I have reserved the interpretation and analysis of the findings for the following Discussion chapter. To protect the identity of the participants, pseudonyms are used for the parents as well as their children throughout the chapter including in the parents’ quotes where they refer to their children.

Prior to beginning the formal interviews, a researcher-administered questionnaire was used to collect some demographic information about the participants and to understand their existing support systems. Table 1 presents the demographic profile of the parents of both cities. This information on the demographic profile and their existing support systems provides the necessary background for the findings that follow.

6.1 Existing support system

In addition to the participants’ demographic profile as described above, the researcher-administered questionnaire also collected some background information on their then existing support system (at the time of the interviews) under the following key headings – ”Home and personal care”, ”Mental and physical health”, ”Social and vocational life”, “Financial security and management”, and ”Decision making.”

Home and personal care

Since one of the eligibility criteria for participation was that the parents should have been looking after their adult child with HCN at home, in all the cases, at the time of the interview, the adult children were living at home with their parent/s. In both groups (Auckland parents and Delhi parents), in about half the cases, other non-disabled

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5 Interviews with Auckland parents were conducted between May and July 2015 and those with Delhi parents, between July and September 2015.
Table 1.

Demographic Profile – Parent Participants

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<thead>
<tr>
<th>Demographic Profile – Parent Participants</th>
<th>Auckland</th>
<th>Delhi</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of interviews</strong></td>
<td>14</td>
<td>18</td>
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<tr>
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<tr>
<td><strong>Average age of disabled child (in years)</strong></td>
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siblings also lived in the same household. Four Delhi parents reported that they lived in a joint family system where either the child’s grandparents or uncles, aunties and cousins were also living in the same house. When asked about who looked after their children’s personal care needs and provided support with the household chores, a majority of the Auckland parents reported that they received some formal support in this
area in the form of publicly funded caregivers coming to their house for a few hours a day to provide care. The number of hours of paid support received differed from family to family. For the rest of the time, the parents themselves provided the necessary care and supervision. The Delhi parents, on the other hand, provided most of the personal care and household support themselves, and over half the parents reported that they received some informal support in this area in the form of assistance from the other members of the family. Four Delhi parents from higher socio-economic backgrounds had employed personal care assistants (whom they referred to as “maids”) to look after their children’s personal care needs and doing household chores. These maids were paid by the parents out of their own financial resources. None of the Delhi parents reported receiving any formal support in this area.

**Mental and physical health**

Both groups of parents reported that they took the primary responsibility of looking after their children’s mental and physical health including taking their children for medical appointments, administering medications, providing them emotional and spiritual support, and behaviour management support. Whilst some Auckland parents reported receiving support from the formally funded support workers in this area, many Delhi parents reported getting support from other family members.

**Social and vocational life**

All the Auckland parents reported getting formal support in the social and vocational area as their child either attended a publicly funded day programme for leisure and recreational activities or some sort of a vocational centre run by a disability service provider. A few children also attended some community based activities/programmes. In a majority of the cases, however, the parents took the responsibility of organising the transport to and from the programme that their child attended. Only one Auckland parent reported receiving informal support in this area from her other, non-disabled, child.

Some Delhi parents reported receiving formal support in this area as they did not need to pay fees for the vocational centres that their child attended. However, a majority of the parents took it upon themselves to provide their children with opportunities for social interactions or leisure activities. As in the other areas, most of these parents also
reported receiving informal support from family and friends, particularly in the area of leisure and recreation.

**Financial support and management**

Almost all the Auckland parents reported receiving some form of financial support from the government. This included various financial benefits their children received towards accommodation costs, supported living, and other disability related expenses; free or subsidised aids and equipment; free or subsidised health care and medical costs; and in some cases, direct funding to manage their children’s home and personal care. In contrast, a majority of the Delhi parents reported receiving no financial support from the government. Only in a few cases, the parents reported that their child received a pension and/or free or subsidised health care in the government hospitals. Unlike all the other areas, where the Delhi parents reported receiving good informal support from family and friends, only a couple of parents mentioned getting any financial support from other family members. When it came to supporting their children with the management of their finances, both groups of parents reported managing it themselves.

**Decision making**

In terms of the support with decision making, a trend similar to the area of mental and physical health was noticed in both groups with a majority of the parents reporting that they primarily shouldered this responsibility themselves. Some Auckland parents reported receiving formal support from the funded support workers and some Delhi parents reported receiving informal support from other family members.

Both groups of parents were also asked about the support they received for themselves as being the parents of adult children with HCN. Many Auckland parents reported that they received formal support in the form of ongoing respite care. Some even reported getting direct funding under the funded family care scheme. The Delhi parents, on the contrary, reported receiving no formal support for themselves and mentioned that they always had to seek support of their family and friends to receive any temporary respite from their caring role. However, both groups of parents reported that when it came to peer support or counselling for themselves, they received it primarily through their own informal networks of other parents of disabled children.

Thus, the summary above of their then-existing support system suggests that the level and type of support received by both groups of parents differed significantly. The formal
support played a major role in assisting Auckland parents in their caring role, whereas, in case of the Delhi parents, the formal support was almost non-existent and it was the informal support of other family members that they found most useful in their caring role. This summary profile supports the premise on which I had chosen India and New Zealand as my study sites – that is, the parents of both countries have access to, and rely upon, a different combination of formal and informal supports in their caregiving role.

The next section provides the necessary background to the data including how it is presented in this chapter.

6.2 Background to the data

The information presented in this chapter primarily intertwines the data collected from four data sets – Auckland parents, Delhi parents, Auckland key informants, and Delhi key informants. As mentioned in the introductory chapter, the primary purpose of choosing the participants from India and New Zealand was to provide a unique insight into what influence does living in countries with varied levels of formal and informal support have on the wishes and worries of the parents of children with HCN concerning their children’s long-term future. Therefore, the findings from the parent data sets are not presented in this chapter as a direct comparative analysis of what one group of parents said versus another but each section provides the information shared by both groups of parents. A summary of the key similarities and differences found across and within the two data sets of parents is then provided in the next chapter with a view to gaining a better understanding of the influence of their available formal and informal structures on their wishes, worries and future support needs.

The purpose of interviewing some key informants from both cities was to get an additional perspective on the issues raised by the parents and to assist with making robust recommendations. The findings from the two data sets of key informants are therefore located together under appropriate sections to highlight their agreement or otherwise with what the parents said. The first two sections on the parents’ wishes and worries concerning their children’s future do not have any data from the key informants as these questions were not posed to the key informants.

Before presenting the findings, it is also necessary to provide a context to the difference in the terminology used by the parents for services available in Auckland and Delhi.
• For Auckland parents a school (educational setting) is different to a day programme (leisure/vocational centre for adults). Indian parents, however, often call even a day programme, a school (place where adult disabled children go to learn different skills). These schools (vocational centres) are often like sheltered workshops for disabled people and some centres pay a minimal stipend to people who work there and some do not. At times, within the same centre, some people get paid and some do not, depending upon their level of contribution.

• Auckland parents’ idea of a residential home is a “group home” shared by four to five disabled people, staffed with support workers to meet all the support needs of the residents. Since there is no concept of smaller group homes in India, for Delhi parents, a residential home is an institution-style residential facility where a large number of disabled people live together and which is staffed with special educators (to teach them skills) and aayas (maid to look after their personal care needs). Many residential institutions set up in India prior to the advent of the Gharaunda scheme by the National Trust still house over a hundred disabled people in supervised and gated premises.

The above explanation provides the necessary context for the participant quotes, particularly containing references to the terms such as school, day programme or residential home. The rest of the chapter presents the key findings of the study.

6.3 Key findings

As mentioned in the previous chapter, the information provided by the participants was first auto-coded based on the broad questions from the interview schedule. The data within each question were then categorised between various themes and sub-themes. For ease of reference, the findings are presented in this chapter with each broad question being the section heading and the key categories or themes within each question form the sub-sections.

6.3.1 Wishes

This section presents the information provided by the parents in response to the question – Tell me about what wishes you have for your child’s future when you are no longer there. The parents were encouraged and prompted where required to talk about their wishes concerning all aspects of their children’s care and support needs. During the course of the interviews, the parents often switched from one aspect of their child’s need
to the other but to maintain a natural flow of the conversation, no attempts were made to interrupt them or provide any set structure. However, for the purpose of reporting, the parents’ wishes are summarised in this section under the headings used earlier to describe their then existing support system.

**Home and personal care**

During all the interviews, while discussing their future wishes in the area of home and personal care, the parents primarily focused on two key aspects: a) Type of accommodation – where they wanted their children to live in the future; and b) Provision of care – who they thought should look after their children’s personal care needs and how.

**Type of accommodation**

The long-term living options for their children that the parents wished for could be broadly classified under four different categories based on the accommodation type – *flatting, own house, family home*, and a *residential setting*.

**Flatting**

About half the Auckland parents expressed a wish for their children to flat with two to three other people with similar disabilities. The parents felt that having a couple of other people with a similar disability living in the same house would not only provide companionship for their children but could also be helpful in providing better-integrated care.

The idea is that there will be about three disabled people living in the same house. So there would be a bigger cluster of support workers looking after all of them. They would integrate into their own sort of family unit – that’s how I see it. (Joanna, Auckland parent)

I don’t see him living in a house with more than one or two people because it’s too unpredictable and especially when you put Autism and disability together it doesn’t work. (Judi, Auckland parent)

Mrs D’souza expressed a view that two to three people with a similar disability living in the same house could also facilitate joint oversight of care by other family members of the flatmates.
So if one goes, like if I die, we know that we are all a group watching over…. That could also be quite a beautiful thing. And maybe our children will be better that way with similar people in a house and then our [non-disabled] children can go and supervise there when we are gone; and somebody else’s children can also go and supervise somebody else’s sibling. (Mrs D’souza, Auckland parent)

None of the Delhi parents mentioned flatting as a future living option for their child.

*Live in own house*

A couple of Auckland parents and a couple of Delhi parents from a higher socio-economic background wished that their children should live in their own home which they might help set up.

But I think a home that was his own so even when we go or move on or pass away that he will have something that there is no ifs, buts and maybes; it’s gonna be his home environment. (Lesley, Auckland parent)

So to that end this place that I am setting up…. I envisage that she would be staying there. (Kanchan, Delhi parent)

*Continue living at family home*

Some Auckland parents and some Delhi parents wished that their child should continue to live in their family home either by themselves or with other family members.

Evan will be very upset if he didn’t live in this house and continue living in this house. (Katie, Auckland parent)

Ideal would be if she can remain with my son’s family but we would make such arrangement that he would not have financial crunch for her. (Shobha, Delhi parent)

Joanna, however, was not in favour of disabled children living with their parents all their lives and felt that it is not healthy to keep the child at home forever as they need to experience a bit of independence like other non-disabled children of their age do.

It’s a much healthier scenario if there is a bit of independence and I look at him like my other two sons where eventually they leave the nest and they are on their own and they have their own circles of support around them and I am just one of the people in that circle. (Joanna, Auckland parent)
Residential setting

A majority of the Delhi parents, particularly those from a lower to middle socio-economic backgrounds were uncertain about future living arrangements and wished that there was some kind of a residential place where their children could stay after the parents were no longer alive. These parents had no clear idea of what such a place would look like and their description of such a place included phrases like “a nice institution”; “nice house – like an old age home”; “a clean and tidy place”; “like a hotel”; “a safe place”; “residential institution”; “similar to a hostel”, etc.

I would wish that she lives in a nice institution because if her brother and sister are not going to do anything then the institution should be there. (Chitra, Delhi parent)

If there is a place like a day care centre or a residential hostel where Sumit can live. If I am not capable of looking after him then we will put him there. (Radha, Delhi parent)

A couple of Auckland parents too felt that a residential home type setting would be an ideal future living option for their children because of the nature of their support needs.

Ryan needs almost hospital care and if we weren’t here tomorrow, he would have to be looked after in a hospital type situation either in a rest home or in a full time care place. (Tania, Auckland parent)

Thus, the parents expressed a range of different views in terms of the ideal living situation for their children when they themselves are no longer alive. As discussed in detail in the next chapter, the reasons for these differences in their views include their own personal beliefs, their financial background, their perception of their children’s health and (dis)ability status, and the availability of, and access to, formal and informal support.

Provision of care

Irrespective of their desire for where the child should live, a majority of the Auckland parents expressed that they would like their children to be cared for by the government funded support staff who are formally trained. They also felt strongly that it is crucial for the support staff to have good knowledge of their children’s disability and relevant specific support needs.
My aspirations will be that she has superb, skilled quality staff. (Rosemary, Auckland parent)

That they would have live-in carers who would be kind and gentle and understood the [diagnosed] syndrome from both the medical side and the emotional side. (Joanna, Auckland parent)

Many Delhi parents who wished that their children should live in a residential home also mentioned that the care at those institutions should be of a good quality and be provided by trained caregivers who understood their children’s needs.

Yes, the caretakers should have understanding of the emotional needs of the kids. The caretakers should be professionally trained such as a special educator. Even if there is a governess at the hostel, they should be specially trained for these kids. (Radha, Delhi parent)

They should get good care. It shouldn’t happen that because every second Saturday the parents come for a visit, so you keep them clean during those days and the rest of the days you give them either stale food or don’t shower them for four days. That should not happen. (Radhika, Delhi parent)

In addition, a couple of Auckland parents also emphasised the need for the support workers to work consistently for a long period with their children and have a peer-type relationship where they understand each other and have a good connection.

So the hope would be over the long term that we could have a support worker who almost became like a peer … and be very connected and there is sense of security and ongoing stability for him. (Lesley, Auckland parent)

Those Delhi parents who wished that their children should continue living in the family home, expressed a desire for their children’s personal care needs to be met by other family members – mostly their non-disabled siblings.

I have told my other son that till the time we are alive, we are looking after him but after us you are the one who has to look after them. (Nita, Delhi parent)

Like there is an understanding between me and my brother that if something happens to me tomorrow, he will take care of him. (Hema, Delhi parent)
The Delhi parents from higher socio-economic backgrounds, however, wished for a family paid support worker to take care of their children in the future.

A maid can be hired for 24 hours who takes care but still remains in the family, she is taken out in the evenings. So those things doesn’t become a burden on or restricts the son’s family’s movement and the life but she is very much part of the family. That type of situation would be ideal. (Shobha, Delhi parent)

Many parents from both groups felt that it would be crucial that some sort of supervision or an oversight of the formal care and support was provided by other family members or friends to ensure safety and quality of care.

Although I wouldn’t want my daughters to have to be too involved, I would hope that they will make sure that he was looked after in the right place and visit him. (Tania, Auckland parent)

Yes, an oversight role of asking the right questions of recognising things – how to check. (Louise, Auckland parent)

One Auckland parent and a couple of Delhi parents also expressed a desire for their children to be married and be cared for in the future by their life partners. A few Delhi parents, however, were unsure as to who would take over the caring role from them and some even wished that their children should become independent in personal care so that they did not have to rely on someone else or become a burden on someone.

That [personal care] we are doing till the time we are there. Once we are not there it is all in God’s hands. (Mr Sethi, Delhi parent)

This is the reason why we bring him here [day centre] so that till the time we are alive, he becomes understanding enough to do things on his own in future. (Mahesh, Delhi parent)

Thus, the findings suggest that, whilst there were differences of views within and across both groups of parents in terms of who should provide long-term care to their children, all the parents expressed a desire for their children to receive good quality care by people who were well trained or who knew their children well. Further, both groups of parents also felt that an oversight of the formal care by other family members would be crucial in ensuring that their children were well looked after.
Mental and physical health
Many parents from both groups wished that their children should continue to maintain good mental and physical health including following their existing diet and exercise regime.

He has a big requirement for physical exercise and so we would need to formalise a plan where that could continue to be provided and health care and so forth. (Lesley, Auckland parent)

She should remain well. If she stays like how she is now, I am also happy with her and we have good times together. (Sunita, Delhi parent)

Many Delhi parents mentioned that whoever takes charge of their children’s personal care, be it a family member or residential staff, they should also ensure that their health related needs are also met.

I don’t know! Now that we are alive, we are doing. Later on whoever keeps her will have to do it. She needs lifelong medicines so wherever she stays will have to do it all. We are not going to be there to see once we die. (Chitra, Delhi parent)

The other wish expressed by a few Delhi parents was that their children should receive free health care including regular health check-ups.

Even when such a child goes to a hospital their treatment and medicines should all be provided for free as this child is not likely to earn for his lifetime; they can’t do anything. The parents also can carry on bearing these expenses for how long? They have other kids too. (Sangeeta, Delhi parent)

One Auckland parent commented that it would be crucial that her child was able to maintain his religious faith as it is vital to his mental health.

Social and vocational life
Key themes that emerged from the discussion with both groups of parents around their wishes for social and vocational life of their children include: they should be able to continue to pursue their hobby; attend a day programme doing activities of their choice; or take part in the community based activities of their choice.
Going to meeting different people and for her to becoming an artist is increasing her self-worth and her sense of belonging in the community of who am I? I am not a disabled person who goes to a disabled place every day. I am someone. I am me. I am autonomous. (Louise, Auckland parent)

Maria being a little social butterfly that she is, she loves to talk, go out into the community and get involved. So she needs to have a bit of energy around the environment she is living in. (Mrs Smith, Auckland parent)

There are many disabled kids who are interested in music. Their future can be made through their hobby. If nothing else, they can at least play at the local temple. (Hema, Delhi parent)

A couple of Auckland parents also mentioned that, in addition to doing activities of choice on a daily basis, they would also like their children to continue to go on a holiday once a year or so, something that they currently do with them.

Some Delhi parents mentioned that it would be important for their children to be able to attend some sort of a vocational centre irrespective of whether they get paid there or not so that they would be occupied during the day and would feel that they are doing something worthwhile.

Many Delhi parents and a few Auckland parents, however, also expressed a desire for their children to earn some money either through self-employment or a paid job using the skills they have. The Auckland parents talked about their children being involved in occupations like working on a farm or doing gardening or doing artwork. The Delhi parents from higher socio-economic backgrounds talked about them setting up a business for their child. Such business ideas ranged from setting up a craft village to a florist shop to a flour mill. Those from lower socio-economic backgrounds, however, either expected government support in setting up a business like running a phone booth or wished that their children should do some simple jobs according to their ability.

So his work should be according [to his liking] – for example, he likes helping others…. If this is what he likes and wishes, he can go ahead in that. I won’t feel shy that my son is working in a hotel serving others and washing dishes. If my son can earn his living by doing even that job then I would consider myself the
luckiest mother in the whole world. At least I will feel that my son is self-dependent. (Radhika, Delhi parent)

I want him to have a small but respectable job where nobody can humiliate him. He can have a simple job where he can earn his livelihood. (Monica, Delhi parent)

The overarching theme was that the parents wished for their children to live a happy and fun-filled life in a stimulating environment and not just sit at home the whole day doing nothing.

It’s outside activities that helps them grow and stops them from being a vegetable. (Mr Smith, Auckland parent)

Financial security and management

In terms of the future source of funds, a mixture of views were expressed by the parents of both groups. Some suggested that they would leave behind enough savings for their child’s future; some expected the government to take complete care of all the financial needs of their child; some suggested that it would have to be a combination of their own personal savings and the support from the government; whereas some mentioned that they had no idea where the funds would come from.

Well, I am not sure what would happen because he will be an adult in his own right without any financial situation, so if he was like that and he was unable to look after himself, I guess he would have to be in a place, someone would have to find somewhere for him and I am not quite sure what happens. I haven’t asked, don’t want to know. (Tania, Auckland parent)

There should be an organisation that can help our kids financially may be through government…. These kids should have so much facility so that whoever looks after them should not have to suffer financially too much. (Sunita, Delhi parent)

One Auckland parent strongly felt that, whilst it is good if the government provides any financial support, the families should not be expecting it and it is their primary responsibility as parents to look after the future needs of their children.
I get surprised at the parents who feel that we have got a disabled child and look the government can’t give us enough to look after this child. You know my view is that hang on, this is my girl, she is mine, I am the number one person responsible for her and I will always feel that way. (Russell, Auckland parent)

A majority of the Delhi parents from lower socio-economic backgrounds expressed a desire for their children to be self-reliant either through self-employment or a paid job.

My only wish is that my kids become self-reliant and should not be on mercy of others. When they grow up, they shouldn’t have to think that my cousin brother will earn and feed me or whatever savings my mom has done for me, I will eat from that. My wish is that both my kids should stand on their feet. (Radhika, Delhi parent)

The parents also expressed a range of different views over who should support their children to manage the funds. Some talked about establishing a Trust to look after the financial affairs; some expected other family members to provide the oversight of funds management; some talked about nominating a legal guardian to take this responsibility on; and some parents had not thought about this issue and were unsure as to who could support their children in managing the funds.

He does have a profound intellectual disability so financial management for example he is not going to be able to manage his own financial affairs. So there is some hope that our daughter or other extended family will be able to provide some guidance and assistance there. (Lesley, Auckland parent)

I really don’t know to be honest. That’s something that the government is gonna have to look at too. That’s the reality of it. (Holly, Auckland parent)

Only one Auckland parent and one Delhi parent mentioned that, with some support, their children would be able to manage their own financial affairs. One Auckland parent expressed a strong desire for her child to be able to have enough funds to not only cover all her disability related needs but also to have sufficient funds to spend on other activities of her liking and to be able to do some personal shopping of choice.

Decision making

A majority of the parents from both groups wished that other family members should continue to support their children with decision making as their future guardian/s.
We already have in place provision if both my husband and I were to die we have a family appointed to oversee him as long as they can and make sure that the care is OK. (Holly, Auckland parent)

His brother will take decisions for him and can take his guardianship. Till the time we are alive we will do it and after that his brother. (Nita, Delhi parent)

A few parents suggested that a Trust they hope to establish for the management of financial affairs should also provide decision-making support especially when it came to major decisions related to service provision or health care.

I am thinking of making a Trust and give them the full power. All my three daughters could be in that Trust and some other people. (Mr Shah, Delhi parent)

One Auckland parent emphasised that it is important that the people who are entrusted with decision making know the child well and have a good understanding of the system.

I have three people that I would like to have a shared guardianship role. All for different reasons – one because she has an extensive work history in [the] mental health sector. She also has been a family friend for a long time and I trust her. The other one is someone who is a mother [of a child with a similar disability] so she knows [the diagnosed] Syndrome and knows all the medical stuff. And the third person is someone who has worked in government level. She knows the pragmatics of the system. So they are all going to ask questions from their own area of expertise. They will all bring their strengths to the table. They don’t have to do any of the day to day care but they can ask the questions and have expectations and will expect accountability and transparency. (Louise, Auckland parent)

With regard to the day-to-day decisions on what to eat and what to wear, all the parents suggested that the person/s providing personal care would also need to support their children with those decisions. Some parents, however, felt that with little support their children could potentially take such decisions themselves.

**Wishes – general remarks**

The parents also made a couple of very important remarks when discussing their wishes for their children’s long-term future. First, one Auckland mother emphasised at the very beginning of the interview that their wishes or aspirations (as parents) may not
necessarily be the same as what their son might want for himself. She asserted that often the parents force their own wishes on their children with HCN and believed that that should not be the case.

Secondly, many parents from both groups also wished, out of despair, that their disabled children should die before them. They felt that their children are unlikely to get the kind of care that they currently provide as parents and that the children would become extremely vulnerable after them.

That’s my biggest wish in life is that she dies before me. I have said to Maxine that not just too soon [laughs] but not too late either…. No, I would not leave her vulnerable to the state and that is a big admission. (Louise, Auckland parent)

I desperately hope that I outlive Sally. (Rosemary, Auckland parent)

First my wish is that something should happen to Jitesh before me. No mother would want to leave her such a child crying. (Hema, Delhi parent)

Many parents who have disabled kids they often think that either you [God] take us or let this person die before us. So that we don’t have to see him getting exploited by others. (Mrs Sharma, Delhi parent)

All these parents dearly loved their children but feared that when they were no longer there to care for them or advocate for their rights, their children either might not lead a good quality of life or in the worst cases, might even be abused or exploited. The following section on the worries provides an insight into some of the fears of these parents.

6.3.2 Worries

This section presents the information provided by the parents in response to the question – *Talk to me about the worries you might have concerning your child’s future when you are no longer there.* Similar to the discussion around wishes, even for this question, the parents were encouraged and prompted where required to talk about their worries concerning all aspects of their children’s care and support needs.

A possibility that their children might be abused while receiving support or that their support needs might be neglected was the biggest concern expressed by a majority of the parents from both groups. Therefore, this section begins with sharing the parents’
concerns around potential abuse and neglect before moving on to their other concerns in various individual support areas.

**Abuse and neglect**

The parents of both groups expressed a big concern that because their children have limited cognitive ability and understanding, they could be easily manipulated, abused or taken advantage of in some form or other. Some parents mentioned that their children have had first-hand experience of abuse in the past, whereas many others mentioned that they either knew of someone who had been abused or had read media stories of abuse against people with HCN. In sharing their concerns, the parents made numerous references to various types of potential abuse including financial, emotional, physical and sexual abuse.

That’s a fear – would another client abuse her, would a caregiver abuse her – emotionally, physically or sexually – you know huge big fears. I don’t like to think about it to be honest, it’s quite a scary thought. (Wendy, Auckland parent)

It’s only that because she is a disabled person, I do not want her to be sexually exploited or misused or ill-treated. (Manju, Delhi parent)

The potential for neglect and abuse is probably my biggest concern. Yeah, I would like this house to be full of cameras, if [I had] my way. (Louise, Auckland parent)

I am also scared that what if they pull my daughter with a force. Those who don’t know her might beat her. There are also some people who think that if I find this person alone, I can misuse or manipulate her. My daughter has gone through such a thing…. If anyone who behaves in such a manner with these kids, they should be hanged. (Sunita, Delhi parent)

One parent suggested that abuse is not always very visible as it often happens in a very subtle way and can take various forms such as people not being valued or communicated with properly.

Abuse is isolation – no value…. And I guess the biggest abuse is just not communicating or talking down to someone like they are not even there; talking to them like they are disabled; and all of that type of thing. I just see that as abusive. I don’t like it and it annoys the crap out of me. (Judi, Auckland parent)
Many parents also expressed a further concern that their children with HCN are more vulnerable to such abuse than others because they are often non-verbal or have limited communication skills and as a result they might not even be able to prevent abuse from happening or report it once happened.

But there is vulnerability in there as it is a huge thing to trust another person to come in and shower your young person with a disability because of their vulnerability they are non-verbal they are not necessarily going to report any kind of abuse for example. (Lesley, Auckland parent)

The atmosphere is not good now-a-days, what if the auto driver takes her somewhere and does something to her, the child won’t be able to even say anything…. People should not take advantage of them because these kids can’t say anything or understand anything. (Sangeeta, Delhi parent)

One Auckland parent commented that, based on her experience, even if these children somehow manage to report the abuse, their stories are not considered credible and hence no action is taken.

Many of our families refuse to get formal support for their kids because they don’t trust the providers, you know there is lot of media coverage about people being abused in care. We have had our own experience twice with Sally and I have been to a complaints body with these cases. And they rarely get upheld because the kids are seen as unreliable witnesses. (Rosemary, Auckland parent)

**Home and personal care**

Similar to the wishes, the worries shared by the parents in the area of home and personal care can also be discussed under two broad categories: a) worries concerning the future accommodation – where and with who the child would live; and b) worries concerning future care – who and how well would they support their child with household chores and day-to-day personal care.

**Type of accommodation**

Some Auckland parents felt that when they are no longer there to advocate for them their children would end up in residential care. Concerns were also raised that they might be forced to live with other people whose support needs might be different.
The first thing is that the government relies so much on parents that if and when we are no longer there what would happen to Jordon? He would be then placed into residential care. (Donna, Auckland parent)

I worry who Lorraine is put in care with. I don’t believe that Lorraine should go into care with people who are violent if she is not violent herself. (Wendy, Auckland parent)

For a few Delhi parents, however, the biggest concern was that, after they were no longer there, their children would have nowhere to live, especially if the government does not set up something suitable for them.

I don’t have a house or anything. If something happens to me today, are my kids going to roam on the streets like some of the other kids that we see in Delhi? That is the biggest worry. (Radhika, Delhi parent)

One Delhi parent from a higher socio-economic background expressed a concern that, if her child could not continue to live in their family home for some reason, then she would have to make a significant compromise to her lifestyle as even a private residential home would not be as good as their own home.

Provision of care
In addition to the concerns discussed earlier around potential for getting abused while receiving care, the other major concern the parents expressed around personal care and support was that the quality of care might not be good. They were worried that the attention to detail that they give when providing intimate personal care might not be given by the support workers as, for them, it is just another task or a job.

I actually have a huge fear that when she is away, is she being cared for to the same standard and the level that I like? Are they gonna put on her thermals when it is cold. Are they going to make sure that she is warm at night and check her feet to see if they are warm? Are they going to wash her hair and brush her teeth every night? Are they going to do those things? (Wendy, Auckland parent)

Even this school [day centre] where he goes to we don’t know how good a care they are taking, whether they feed him on time or not, the Lord only is watching, we are not watching. There is a lock at the gate, once you go in they will ask you
to sit and then once the madam comes out you can talk. They won’t let you see where your child is. (Mr Sethi, Delhi parent)

The other concern that the parents of both groups expressed around personal care was that if adequate care and support were not provided, accidents could happen and it could also put the safety of the child at risk. For example, the child might get burnt if not supervised well when making a hot drink.

Similar to their uncertainty around future accommodation, some Delhi parents also expressed a concern that they were unsure as to who would support their kids with their personal care needs when the parents were no longer alive. This concern was more grave for people from lower socio-economic backgrounds as they could not even afford to hire home help or a full-time maid. So they were worried that their children would not have anyone to provide care if their other non-disabled siblings were unable to take care of them for some reason.

His brother and sister don’t think much. How will they look after her? If the sister decides to look after him, her in-laws might have an objection. If the brother decides to do [this], then his wife might have an objection. So that’s what we worry about…. Now I have realised that I am turning grey, he is growing up and who will look after him after us. (Mahesh, Delhi parent)

**Mental and physical health**

The biggest concerns expressed by the parents around their children’s long-term health and well-being was that the support persons and the health professionals might not understand their children’s medical condition and as a result their health-related needs might not be met adequately. The parents talked about them having to do a lot of explaining at medical appointments. This could lead to a potentially dangerous situation as the correct treatment might not be provided in a timely manner if they were not around to provide the necessary information.

With health related matters I think the hardest part would be that somebody will have to speak on John’s behalf and often even the specialists are unfamiliar with the condition so I am the one first giving them the medical information. (Joanna, Auckland parent)
Our kids should be under care of such people who look after every single need of theirs. Like, if they are sick or they need something else? How to find those things out?… So we need a doctor who can understand all these things. (Sunita, Delhi parent)

Many Auckland parents, particularly those who had no family support, expressed a concern that, after the parents died, their children’s emotional well-being might be sacrificed.

You can buy effectively or the government can buy for you an environment which is really safe, clean, warm, dry, daily cares, food on the table, washing is done, you know, that kind of thing but it doesn’t provide for the other component that is emotional security and family and relationships – that’s the hard bit to put in. (Lesley, Auckland parent)

Another concern for the parents of both groups was that their children’s health would deteriorate in general as they get older.

Social and vocational life
Many parents expressed a concern that their children would not get any choice and be forced to engage in unwanted or undesirable activities, or to stay at home doing nothing. This could lead to their children leading a non-stimulating and dull life.

There is one big huge thing. He has to be occupied otherwise he goes to his room and that is the nest or whatever you call it for depression. Just to sit alone in the room. So that is a huge issue that who is going to keep thinking that he should be occupied. (Mrs D’souza, Auckland parent)

They [the day centres] are not interested whether the child is doing something or not. You just send them, they will make them sit the whole day and you have to just go and pick them up in the evening. (Mr Shah, Delhi parent)

A couple of parents also expressed their concerns around a lack of suitable day programmes for adults with HCN:

There is nothing around here. There is only one leisure centre in North Shore but how is he going to get there? (Donna, Auckland parent)
There is no such place in Delhi at all. We need to develop recreational or leisure centres. (Shobha, Delhi parent)

**Financial security and management**

In the area of financial security and management, the parents shared their concerns in two respects – the source of future funds for their children, and the support needed by them in the management of those funds.

One of the biggest concerns expressed by a majority of Delhi parents, especially by those from lower socio-economic backgrounds was the uncertainty around the future source of income to meet their disabled children’s needs after the parents had passed on. The parents seemed completely in the dark about their children’s financial future and expressed that as their single biggest worry:

But there is nothing such [like funded services] available in reality, it all is just bookish talk….If you can afford to pay for the care of your child, then that’s the only thing that works, there is nothing else. (Hema, Delhi parent)

I don’t have my own house, my husband doesn’t stay with me, and whatever savings I had I have invested it all in my husband’s treatment. My worry is that I don’t have anything. What will I do for these kids? (Radhika, Delhi parent)

The worry is that now we are doing [the task of providing financial support] but who will help him financially in the future? In today’s expensive days, how much can we even put together for his future? If he doesn’t earn, who will feed him? (Reshma, Delhi parent)

Many Auckland parents were also concerned about the lack of funding and mentioned that they cover out of their own pocket the shortfall from the government funding to meet their children’s additional disability related needs and other social needs. They expressed concerns around how that shortfall would be met when they were no longer there, and the impact it might have on their children’s lives if that shortfall was not met.

Yes obviously if we lost all our money that will be a concern because to pay for the extra $300 a week in extras, where is that gonna come from? To pay for petrol and bus and recreation and food, where will that come from? (Judi, Auckland parent)
I think we need to find something that generates income so he does have a little bit and he is not limited by money because we don’t know how the government assistance is and you can’t rely on that. (Donna, Auckland parent)

In terms of the management of funds, some parents expressed a concern that the money that their children would have might not be spent appropriately on meeting their needs or on sourcing the things that they like.

The money not being used to her full benefit and not even being advocated. Yeah, I wouldn’t want her to be stuck in the poverty trap of no you can’t go to the city for dinner because you don’t have enough money or you can’t go to the movies, we can’t drive out to Muruwai for hot chips and watch the sun go down because we have to have shower by 4.30 because that’s what your schedule says….It’s losing that spontaneity of life where she has to live a services programme and not her life. (Louise, Auckland parent)

The hardest thing to contemplate is when my wife and I are dead and gone and she is still alive, what happens then? That somebody will obviously get whatever funding is available to support her and we have to trust that that person will apply the funds reasonably towards her needs and they are not going to say “oh goody goody we have got this money now we can go out to the casino” [laughs]. (Russell. Auckland parent)

**Decision making**

The only major concern the parents expressed around decision making was that the person/s taking the decisions on behalf of their children might not understand their children’s communication and as a result the decisions taken might not reflect their children’s wishes or best interests.

Well that’s a huge one. That’s the whole communication there and that’s the one I have been fighting for – a right to his voice. (Joanna, Auckland parent)

For some Delhi parents, the concern in this area was also similar to the other areas as in they were unsure of who would support their children with decision making after the parents were gone.
**Worries – general remarks**

In addition to the worries discussed above related to the individual support areas, the other general worries expressed by the Auckland parents included a concern that their children may not continue to get their existing support in the long term; that people wouldn’t be able to understand their children’s communication; and that their children would have less choice and control when they are not around to advocate for them.

The problem is that she doesn’t have a voice so she can’t say that she likes this and doesn’t like that or she is not as clear as you or I. So whoever is looking after her needs and caring for her I want them to have that ability to understand what she wants to tell them. So for me the biggest issue is communication – that if people can take the time to find out what’s Julie is really thinking. (Russell, Auckland parent)

A large number of the Delhi parents expressed a general concern around the overall well-being of their disabled children and the future uncertainty:

The main worry is that tomorrow if something happens to me what will happen to him? His day to day system who will manage? People say that it will all happen but a mother would always like to see in front of her eyes…. (Hema, Delhi parent)

There is no certainty of life, so long as we are managing it’s OK but who will do it in the future, that concern is always there in the mind of every parent. (Sangeeta, Delhi parent)

Overall, their children’s limited ability to communicate their wills and preferences, vulnerability to potential abuse and neglect in all areas of life and limited capacity to speak up for their own rights were the key reasons of the parents’ worries concerning their children’s future.

**6.3.3 Desired changes**

The parents were also asked to share their views on the changes required in their then-existing support system that could help in fulfilling their wishes and reducing their worries. The changes proposed primarily included either the actions they needed to take themselves during their lifetime and/or the actions they wanted the government to take. Further, the changes proposed differed significantly from parent to parent within and
across both groups of parents depending upon their individual circumstances and hence to adequately capture them all, the changes are presented below in the form of a list of proposed future actions required under each support area.

**Home and personal care**

*Changes sought by the Auckland parents*
- Check out the suitability of the available residential options
- Work with the government to set up an independent house for the child
- Get professional support in life planning
- Find appropriate support staff or agency that could provide personal care
- Approach suitable agencies to assist them with the screening of the support staff
- Train the support staff themselves to ensure the care is done to an appropriate standard including creating video resources on how it needs to be done
- Train the child to be more independent in the area of personal care
- Get a family member from overseas to work with their child as a live-in carer
- Make family expectations and values very clear from the start with potential support workers to prevent potential abuse and neglect
- Make the child more aware of what abuse looks like and teach them about keeping safe
- Government to invest in more staff training specifically in the area of HCN
- Government to install CCTV cameras in disabled people’s homes
- Government to require the service providers to undertake frequent unannounced spot checks of disability homes

*Changes sought by the Delhi parents*
- Set up or leave behind a home for their disabled child
- Train their non-disabled children or other family members in caring for their child
- Government to open more residential homes
- Government to invest in more staff training specifically in the area of HCN

**Mental and physical health**

*Changes sought by the Auckland parents*
- Train staff/professionals in communicating with their child – how to identify the triggers, what different gestures and sounds mean and so on.
• Provide written guidelines around how best to take care of their child’s health including provision for ongoing check-ups
• Find a specialist who could work with HCN adult and carry over the care from a paediatrician

Changes sought by the Delhi parents
• Train their non-disabled children or other family members in looking after the health of their child

Social and vocational life

Changes sought by the Auckland parents
• Widen the child’s social context – create strong relationships – create circles of support around the child
• Start a little club in the house where other disabled people could come with their support workers to socialise with their child
• Government to ensure that suitable funding continues beyond school so that the child could continue to take part in social activities or day programmes

Changes sought by the Delhi parents
• Set up a small family-run business for the child
• Government to open more vocational centres
• Government to open more day centres for leisure and recreational activities
• Government to offer jobs and/or self-employment opportunities to disabled people

Financial security and management and decision making

The changes discussed by the parents in the areas of financial security and management and decision making were similar and hence are presented below together.

Changes sought by the Auckland parents
• Prepare a will – transfer funds/house to the child’s name
• Set up a trust
• Appoint someone as a legal guardian to manage financial affairs and provide decision-making support
• Leave written instructions for the successor/s on what to do
• Talk to the extended family about who will play what role in the child’s future
• Government to ensure that appropriate funding continues to meet 24x7 support needs of the children with HCN
• Government to ensure that the Individualised Funding (IF) carries on so that the child has choice and control

Changes sought by the Delhi parents
• Prepare a will – transfer funds/house to the child’s name
• Set up a trust
• Appoint someone as a legal guardian to manage financial affairs and provide decision-making support
• Government to provide more financial support to disabled children

Changes – general remarks
In terms of the other general changes, the parents talked about a need for raising community awareness, a need for joining parent support groups for better exchange of information and ideas, and about investing time in learning about their children’s abilities rather than focusing only on their disability. There were also a number of parents in both groups who were unsure of what changes they would need to make. For some, it was a matter of trialling a few different options and then deciding the way forward and for some others, the proposition “When I am no longer alive” was still a question for the very distant future and they had not thought much about it at all.

I really don’t know. Because I am not looking at it right now. To me what you are saying is all in the future…. So that’s still very hypothetical to me. (Holly, Auckland parent)

One Auckland parent described the plight of the parents of the people with HCN in a humorous way by suggesting an out-of-the-box idea to improve their situation and then also explaining why that idea would not work.

I know! [gets very excited about the idea] A minister in the parliament with a child with severe disabilities [laughs] – now that’s where some changes would happen. Yeah, it really would because then they will be walking that mile. But then they probably wouldn’t be in parliament because they are too tired [laughs]. (Wendy, Auckland parent)
Thus, whilst some parents had given serious thought to their children’s future and had a fair idea of what actions would be required to secure this; some others felt that it was too early to start thinking about their children’s future beyond parents’ lifespan; and a few parents had just left it all to destiny.

6.3.4 Informal support

This section presents the information provided by the parents in response to the question – *What are your views on the significance of informal support for severely disabled children whose parents are not there?* Both Auckland and Delhi key informants were also asked to talk about their views on the significance of informal support in the lives of adults with HCN and their families. The findings of my discussion with the key informants is also presented at the end of each relevant sub-section to establish the consensus, or otherwise, of their views with the parent participants.

At the beginning of the interviews, while collecting information on their then-existing support system, the parents were explained the meanings of the terms “formal support” and “informal support” in relation to this study. However, for this question, the parents were again reminded that informal support comprised any and all types of voluntary support received from family, friends, relatives, neighbours or wider community in any form. It was also made clear to the parents that this question was not intended to discuss their specific situation – i.e., whether their children were likely to receive any informal support or not, but to express their views in general on the role that informal support could potentially play in the future lives of the adult children with HCN. While some parents did talk about informal support in general, many parents found it difficult to keep a broader focus and knowingly, or unknowingly, kept turning the discussion back to the role of informal support in various specific areas of their own children’s care and support needs. The data presented below combine both their general views on, as well as personal experiences with, informal support.

Based on the type of information shared by the parents, their views on informal support are presented below under three broad categories – the *significance* of informal support in the lives of adults with HCN; the *issues* with or challenges in accessing informal support; and the *suggestions* on improving access to informal support.
Significance of informal support

A majority of the parents from both groups, including those who did not receive much informal support themselves, were of the view that informal support could play a significant role in the lives of adults with HCN and their families. The following sub-themes emerged around the significance of informal support.

Most helpful in leisure and recreation area

Many parents from both groups felt that informal support could play a very significant role particularly in the area of leisure and recreation. Friends, family and even neighbours could spend some quality fun time with the child doing social activities such as playing games or going to movies or outings.

Informal will be more leisure, recreation, visiting places and friends. I think it’s really about going out with a bunch of friends and go to the zoo and things like that as opposed to going on their own there with a carer. (Joanna, Auckland parent)

Yes – for going out somewhere – for example, if someone is going out in a vehicle somewhere I will tell them to take Jitesh with them and they will do it. There are many people who live close by and are very attached to Jitesh, so sometimes they will say let’s go for a film I have some extra tickets for you and Jitesh. So I get this kind of support. (Hema, Delhi parent)

Significance in other support areas

The parents also talked about the significance of informal support in other support areas. For example, a few parents felt that emotional and spiritual support provided by people from the informal network could be crucial in the area of mental health.

We have some very good close friends who provide emotional, spiritual and social support which is really vital. They are vital relationships to maintain because that can affect someone’s quality of life. (Louise, Auckland parent)

Similarly, many parents felt that having good connections and relationships with people in the community could be helpful in avoiding loneliness and isolation for disabled children particularly when their parents are no longer there.

Of course it’s just so unhealthy for them to be isolated. So to be part of an extended family or community is absolutely essential and it shouldn’t even be
considered that they are ever deprived of that. I think it’s invaluable, I think it’s one of the things that I have used is that it takes a global village to raise a child with [the diagnosed] Syndrome. (Joanna, Auckland parent)

Even the child feels that without my parents there is someone else there too. They understand relationships too. (Gita, Delhi parent)

Many parents from both groups also emphasised that having access to informal support could be particularly important during one-off emergency situations:

Occasional thing like, I have asked someone to come with me to medical appointments occasionally with Sean because he is too noisy and awkward and sometime you actually need to restrain him a bit. (Barbara, Auckland parent)

If I have to go to hospital, can you please drop me to the auto as she is unable to walk. So these kinds of support can be easily available informally. And I do get such support. (Sunita, Delhi parent)

A couple of Delhi parents suggested that informal networks, particularly other family members, could also provide one-off financial support in an emergency situation.

Oversight of formal support
As discussed in the next sub-section, whilst many parents felt that it was inappropriate to expect the informal network to provide direct personal care for their children, they did however, feel that it could play a vital role in providing oversight of the safety and quality of formal care including helping their children in the management of financial affairs and providing decision-making support.

Some other family members can take care like supervise but it is difficult for them to take full charge. (Monica, Delhi parent)

There could also be a Trust of nice people who ensure that the kids are well looked after. They will also make sure that the kids are not misbehaved with. (Radha, Delhi parent)

Similarly, a couple of Auckland parents also felt that having people in the informal network who know the system well could also help in battling with the formal system.
**Respite for family carer**

In addition to being helpful to the child in various support areas as discussed above, some parents suggested that informal support could also be helpful in providing respite for the family carer.

I have got a sister I can ask her to come and stay if I really want to go and do something. (Barbara, Auckland parent)

I think family is really good. My brother just provided me respite this weekend. I don’t need respite care but it was nice to get out of the house. (Wendy, Auckland parent)

The informal support can come for respite care also. If I need [time] off for five days, that respite care can come from informal support also. (Shobha, Delhi parent)

**Provided out of genuine love and care**

Finally, a couple of Auckland parents asserted that informal support is more significant than formal support as it is provided out of love and genuine care for the person as opposed to just doing a job.

What an institution would never provide is this humanness, the family spirit, the love, the hugging – all the things that are basis of being a human being. (Judi, Auckland parent)

I think they are extremely valuable for everybody because they are often done out of generosity or love or friendship; whereas with the formal support, there are lots of good people there but it’s a job for them. (Barbara, Auckland parent)

**Key informants’ views**

The key informants were also asked to express their views on the significance of informal support in the lives of adults with HCN whose parents are no longer there. The findings of my discussion with the key informants are now presented.

A majority of the key informants from both Auckland and Delhi also expressed a view that informal support could be most helpful in the area of leisure and recreation. One Auckland key informant described the role of informal support as “icing on the cake” with the cake being a fully established formal support system.
But the informal support will put a bit of icing on it. Take them out, maybe do a bit of shopping, do a bit of leisure activities, just come and sit with them and maybe watch a bit of TV with them or whatever. (Mr M, Auckland key informant)

The key informants also talked about the role of informal support in the areas of providing an oversight of service delivery and safety, support with decision making, providing emotional support and general friendship, and avoiding loneliness and isolation. One Delhi key informant highlighted that, in the Indian situation where formal support is generally non-existent, the informal support becomes all the more significant as it provides parents with a larger pool of people to rely upon.

So if support is required, it is the duty of all around the person to provide that support – it may be parent, it may be friend or neighbour, or local level guardian, or local religious person, or community worker, or grass root worker – anybody. So informal support is much more significant than formal support. (Mr B, Delhi key informant)

Thus, by and large, the views of the key informants aligned with those of the parents in relation to the significance of informal support in the lives of the people with HCN.

Issues/challenges with informal support

Whilst parents were not specifically asked to talk about the issues or challenges, their discussion alluded to a number of issues with, or barriers to getting, informal support, particularly in relation to the support for adults with HCN. Key sub-themes that emerged from this discussion are now presented below.

Intimate and complex nature of care

The intimate nature of the care required was reported as the biggest potential barrier to their children getting informal support. The parents felt that due to the severity of their children’s disability, the level of care required by their children was too intimate and often too complex to expect people from an informal support network to provide it.

I don’t have family who would even be capable of looking after Maxine. It’s only really my close friends but I would never want to ask them to take on such a huge role, yeah. (Louise, Auckland parent)
It may be different for lesser disabled people in that they might have [support of] aunties and uncles and neighbours and things. But those of us who have severely disabled children, none of those people are able to provide or very rarely are able to provide that informal support. Especially if they have serious medical conditions which often many of our kids have. (Rosemary, Auckland parent)

In the area of personal care, I don’t think informal support can help. (Nita, Delhi parent)

Physical high needs where the person is to be fed and all that, I don’t know if an informal system will take care of it. It has to be formalised. (Kanchan, Delhi parent)

Further, as mentioned earlier, a number of parents suggested that informal support could play a big role in the area of social activities. However, a couple of parents elucidated that, while it may be true for other disabled people, when it comes to supporting adults with HCN, people often cannot help even in the social area as they might be required to provide personal care during those social interactions. Thus, for adults with HCN the role of informal support gets even further restricted.

I think it’s unrealistic to expect people to provide informal support for the level of needs that Jordon has because no matter what you do, if you spend time with him, you need to be able to do toileting and I think it’s not right to expect that from people…. So Jordon does not have informal support. (Donna, Auckland parent)

A couple of Auckland parents also pointed out that, whilst it is easier to get informal support when children are younger, as they get older their care becomes more complex and as a result the support gradually diminishes.

I think it is easier to get support around younger kids because they are smaller and they look cute and those sort of things. (Rosemary, Auckland parent)

We have had a lot of support at the beginning. But as he got older it just drifted away. (Holly, Auckland parent)

*Sibling have their own lives*

In terms of the role that their non-disabled children could play in their siblings’ lives,
there were differences of opinions within and across both groups of parents. Whilst a couple of Auckland parents felt that their other non-disabled children should take on some responsibility after the parents pass on, many others felt that they should be allowed to lead their own lives and not expected to look after their disabled siblings.

If they had siblings, I don’t think I would put that on them either because I think it’s quite hard for normal siblings of disabled kids to have that pressure of looking after their brothers and sisters for life. I think it’s good for them to have their own lives as well. (Barbara, Auckland parent)

So, if we were to die tomorrow in a car accident, I wouldn’t want my two daughters to have the responsibility of suddenly having to look after him. They have never had this responsibility and I don’t want them to have it … why should they be laboured with it? (Tania, Auckland parent)

On the other hand, a number of Delhi parents were of the view that their other non-disabled children should play an active role in their disabled siblings’ lives after them but felt that their children’s future life partners may not let that happen.

But then we don’t know about future because it would depend on what kind of house they [siblings] get. If their partners are understanding it’s good, otherwise now-a-days no one wants to do things for others. (Reshma, Delhi parent)

If the sister wants to do something, the in-laws might say that you also leave our house and fend for yourself because this boy troubles us day and night. We can’t do such a thing. (Mahesh, Delhi parent)

For this very reason, one of my study participants Ms Sethi, who took over the role of the mother of her disabled brother after their mother passed away, mentioned that she had decided to remain unmarried so that she could continue to take care of her brother.

*Shrinking family and community spirit*

Many parents mentioned that the life is too fast now-a-days and people are too busy in their own lives and hence have no time to provide support to their disabled children. They also felt that people in the community have also generally become less sensitive towards the needs of the others and are always preoccupied with thinking about themselves.
There is just no one. People are not queuing at the door to provide the support for free – it’s not realistic. (Donna, Auckland parent)

See, [for] those who do not have parents – when their parents die, the relatives die along with them. This is true. Very few, may be two to three out of hundred who would help such children. (Hema, Delhi parent)

In a similar context, a couple of Delhi parents mentioned that the joint families are either no longer there or are not providing as much support as they used to in the past.

See the thing is in India this [joint family] system is also extinct because firstly, the uncles are all now staying separately. Secondly, even if they live together, they don’t do it. They can just motivate the child but they can’t do more because they don’t have time. Even I don’t have time so what to talk about others. (Mr Sharma, Delhi parent)

_Physical and attitudinal barriers in the community_

Community could potentially be a great source of informal support, however, many parents felt that both the physical and the attitudinal barriers make it difficult to access the necessary support from the community. As discussed later in this chapter, people are either scared of disability, or have negative stereotypes, or are just plain ignorant and, as a result, they prefer to stay away from disabled people instead of being helpful.

I think people are scared. Even the people at our church, they see us every Sunday but they are still scared. How do we talk to him, or how do you do this or how do you do that? Ohh, you are so wonderful. Wouldn’t it be nice if they said hey, could we have him for a day or three to four hours, just to give us a break. (Holly, Auckland parent)

And the beach – we are very isolated and cut off from all those sort of things which most families enjoy the most about New Zealand – we are cut off just because of those sort of [physical access] barriers. (Joanna, Auckland parent)

Such kids don’t get informal support and they also don’t get respect. Very few people help such kids. (Rita, Delhi parent)

As a result of such attitudes, a number of Auckland parents and a couple of Delhi parents mentioned that they do not feel like asking favours from others because people
then might help out of a sense of obligation as opposed to doing it of their own free will.

I don’t want people feeling sorry for me because I have got a disabled daughter. That’s not what it’s all about. (Russell, Auckland parent)

The issue of informal support is a huge one because in disability you often feel like you don’t want to ask anybody, you don’t want to impose. You don’t want anybody to do things out of sense of obligation or a sense of pity so you want to avoid that…. Freely given relationships. That’s the ideal – freely given relationships. (Lesley, Auckland parent)

One Delhi parent, however, was of the view that one is more likely to receive informal support from the disability community, in particular from the families of other disabled people.

Those who have such a kid in the house and have experienced it first-hand will do it but otherwise no one else will do it. (Ms Sethi, Delhi parent)

Unreliable or unsustainable in the long run

Finally, many parents felt very strongly that, whilst informal support could work on an occasional basis in certain situations, one could not rely on it as the main source of support and that it would be unsustainable in the long run.

And I guess when things don’t go the way that we would want it with his plan then you are gonna lose your relationship because how do you express to the person thanks for your help but your help is rubbish, or it’s sympathy or something else. (Judi, Auckland parent)

People can do a little bit – but how will they do it? It’s not possible. You will give funds two to four times…. People do have religious or supportive nature but you can’t rely on that. (Mr Sharma, Delhi parent)

Key informants’ views

A number of key informants also expressed a view that informal support cannot be of much help in the areas of personal care as it requires a high level of dedication and commitment which it is often not possible for the informal network to provide.

That [providing personal care] requires a lot of dedication – a lot of sacrifice – giving your time constantly because this is not occasional. So that’s very difficult
task to achieve. That is a very difficult expectation from the informal support.
(Mr A, Delhi key informant)

The key informants also talked about the issues of people being too busy in their own lives, the communities not being as close-knit and supportive as they used to be in the past, and about diminishing support as the person gets older. One Delhi key informant also talked about the issue of disintegration of the joint family system in India and its impact on the support needed by the people with HCN and their families.

Ironically what happens is that the family system is disintegrating. There are nuclear units which are coming up so that support system is not readily available. Because within joint family systems, a person with a disability was never a concern but today because there are nuclear units, it’s the most worrisome concern for the parents that what happens to my child after me. Because they know that there is no [formal] support system. (Ms C, Delhi key informant)

My discussion with the key informants also identified some additional issues and facilitated a better understanding of some of the issues raised by the parents. In relation to the role of informal support system in providing an oversight of formal care and assisting a disabled person with the decisions related to service provision, a couple of Auckland key informants felt that this could become a very difficult role for someone to take on as the New Zealand formal support system was very complex to get one’s head around.

Yes, I think there is a place for informal supports but the system is so complex in terms of health and social supports that it’s quite difficult to navigate and most families take a long while to learn how to navigate a system. (Mr I, Auckland key informant)

The parents identified some difficulties associated with getting informal support in the area of personal care. A couple of Delhi key informants, however, commented that even if informal support was available in the area of personal care, the parents should not rely on it too much as it might not be of a satisfactory standard. They felt that people with HCN require care to be done in a very delicate and sensitive manner and informal support often comes from untrained people making the person vulnerable to poor quality care.
Another significant risk factor associated with the quality of care that the key informants talked about relates to the issue of informal support being unrealistic and unreliable, a view that the parents also referred to. They were of the view that, in a formal support situation, one can demand care at a certain time and of a certain quality. Whereas, with informal support, for some reason if the person was not available to provide support on a particular day, one would not be able to demand that they come. Similarly, if the person was not doing a good job, it would be difficult to make a complaint about their quality of care. The care receiver in this situation becomes dependent upon the generosity of the person providing the care as opposed to receiving good quality care as a matter of right.

Formal support you have assurance. In informal support there is no guaranteed assistance. So suppose somebody is busy otherwise then you can’t demand anything, you have to adjust. But in a formal support it is assured. This is the crucial distinction. (Mr E, Delhi key informant)

Many Auckland key informants also identified certain other risks of relying too much upon informal support, especially on the immediate family for providing lifelong care. They felt that such a family expectation may create issues in their relationships, they may face health issues once they are no longer physically able to provide care, and that they may just become their lifelong carer as opposed to being a mom or a dad or a brother or a sister and enjoy good quality time with their family member without having to do all the caring.

Thus, the key informants provided added insight into some of the issues identified by the parents with informal support.

**Improving access to informal support**

During the course of the interviews, the parents also volunteered some ideas on what they could do themselves to improve future access to informal support for their children. Following are some of the key ideas or suggestions that the parents came up with.

*Establish better network with the community*

Many parents commented that they themselves needed to establish better networks and relationships with the people in the community. They felt that it becomes easier for someone to offer help if they know the family and the person well and therefore, the parents should interact positively with the community when they go out and about with their children and should take an active part in raising community awareness.
I wish there was a perfect formula to secure informal support or unpaid supports and good relationships. Having good relationships have paid dividends for us because people think that this is a good family, I like Kevin, the parents are really approachable. (Lesley, Auckland parent)

I think the community is the key word for the vision that I have for John’s future. It’s very, very important that he is part of a community so that everybody not only learns to value him and get something back from him but that he also feels valued. (Joanna, Auckland parent)

Such support will only be possible when we take our kids in such environment and keep talking to people. For example, if the neighbours’ kids are playing every day you shouldn’t think that if my child goes to play with them they will be disturbed or the neighbour won’t like it. … We have to do a lot of awareness work and tell people that you should help such children. Newspapers and magazines should also write things about our kids. (Sunita, Delhi parent)

**Secure the child’s financial future**

Many Delhi parents felt that it might become easier to get informal support if the child was financially secure. They suggested that the parents should either leave enough funds in their child’s name or ensure that there would be sufficient ongoing funding from the government to meet all their needs. People then might be more willing to provide support so long as they do not have to spend money.

If there is some help from the government then even other relatives will be interested in providing some help…. They will think that we don’t need to do much, we just have to take him there and get things done and come back. Otherwise, if they think that I will have to put in money to get it done or run around to get things done then they take a back step. (Mr Sethi, Delhi parent)

**Have early and open discussions with other non-disabled children**

One Delhi parent suggested that if the parents expect their other non-disabled children to look after their disabled siblings after parents die, then they should have that conversation with their children as early as possible and in an open and honest manner.

In some houses parents don’t talk face to face to their other children about the disabled child’s future. We motivate our children to have a discussion on our
face and say that if you don’t discuss things with us how would we know that after we die how are you going to look after your brother. (Mrs Sharma, Delhi parent)

Key informants’ views
A couple of Auckland key informants also felt the need for the parents to build networks in the community to have better informal support for their children in the future. However, they further emphasised that some parents might need help with that and the government should actively assist such parents in developing a network of people or circles of support around their disabled children while they were still alive. They also felt that it was crucial to have more than one person forming part of a disabled person’s informal support network as otherwise that person might be overburdened resulting in negative outcomes for both.

Many Delhi key informants expressed a view that raising awareness in the community could go a long way in improving access to informal support and that the government should work closely with the NGOs to ensure continual access to informal support in the community for these families.

Informal support – general remarks
A couple of parents and key informants from Auckland made one very important observation in relation to informal support. They mentioned that availability of, and access to, informal support often differs from family to family, culture to culture and society to society.

It’s luck – it comes down to the luck of the draw – luck of the family you are born into – luck of where you live – because if you are lucky then you have family who will help you and who are involved in the person’s life. (Louise, Auckland parent)

I think it varies according to the family. So there are some families who because of the nature of their personalities engage widely and in a wider social construct and therefore the person with a disability becomes connected to that larger social construct. The other families tend to be more insular and so their child with a disability follows that pattern. In rural New Zealand, I think it’s possibly a bit different because you do get a wider set of supports often in rural locations. It’s a bit like the feudal system and more of a village mentality. The person becomes
known in the community and has a wider set of supports because of that. In urban New Zealand, I think people become very isolated and I think in that situation there is a much higher reliance on public support systems. (Mr I, Auckland key informant)

One Auckland parent also suggested that schools and colleges could also become a potential source of informal support for the families.

If there wasn’t a cost and if it was some voluntary – like senior school girls – to be able to offer their services to families like ours, whereby they can come for two hours after school as part of the term’s volunteer work which looks good on their CV and it’s mutually beneficial. I can see something like that really working. (Mrs Smith, Auckland parent)

Finally, my discussion with the key informants also highlighted a very interesting interplay between formal and informal support systems. They suggested that, to achieve the goal of successful life outcomes for people with HCN, both systems cannot work in isolation and they must work hand-in-hand at every step of the way. This interplay between the two systems is discussed in detail in the Discussion chapter. My findings on the role of formal support are now discussed in the next sub-section.

**6.3.5 Formal support**

This section presents the information provided by the parents in response to the question – *What are your views on the significance of formal supports for severely disabled children whose parents are not there?* The parents were reminded that formal support comprised any and all types of publicly funded support including direct financial support to them or their children, any services provided through a service provider funded by the state, or any other support schemes provided directly by the government. The parents were also encouraged not to restrict their answers to the support they received at the time but to share their views on the broader role of formal support in the lives of children with HCN whose parents are no longer there. Similar to informal support, the information shared by the parents on formal support was also categorised under three key themes – the *significance* of formal support in the lives of adults with HCN; the *issues* with or challenges in accessing formal support; and the *suggestions* on improving the use of, and access to, formal support for the people with HCN and their families.
Significance of formal support

In terms of different support areas, many parents from both groups commented that the formal support had a role to play in all the areas of a person’s life. They felt strongly that the government should take on the full responsibility of the overall care and well-being of disabled people, especially when their parents were not there and there was no one else to look after them.

Of course if I am not here then all aspects. Provided they are guided by Evan. (Katie, Auckland parent)

I think in everything for someone with a severe disability. All aspects. (Judi, Auckland parent)

All areas – financially, socially – especially if you talk about when parents are not there, then all areas. (Monica, Delhi parent)

If parents can’t do and other family members also can’t do then it’s very good if government can provide support. Their clothes, food, medicines, all areas can be looked after by government. There is a lot of significance of government support for such kids. No one is going to give out their salary for such kids but if the government can help that will be really good for us. (Reshma, Delhi parent)

Some parents also talked about the role of the formal support in certain specific areas. For example, in the area of mental and physical health, the Auckland parents talked about getting professional behaviour management support, mobility equipment, and medication, whereas the Delhi parents talked about getting free health care, medical insurance schemes for disabled people, and getting priority treatment so that they do not have to wait in long queues at the hospitals.

So what should be publicly funded would be their ongoing use of equipment, the maintenance of the wheelchairs and also looking at things like mobility which is not necessarily just wheelchairs. (Joanna, Auckland parent)

The government should also provide good medical facilities through insurance schemes. That way the institution who is going to take care of the child also does not need to worry about future medical expenses of the child. (Mr Sharma, Delhi parent)
In the area of social and vocational activities, both groups of parents talked about the significance of publicly funded day programmes, and some Delhi parents talked about vocational centres where their children could learn some skills.

You do need formal support for things like Organisation A and Organisation B [names two Auckland-based day activity centres] and so on because, without that quite frankly there wouldn’t be an option. (Russell, Auckland parent)

The government should do that as well. They should have some [vocational] centre. Today for running the industries they have started a one window system that everything you need to start an industry can be done from that one place. Then why can’t they do something similar for such kids? Aren’t they part of our society? (Mr Shah, Delhi parent)

In the area of financial security and management, while the Auckland parents emphasised the importance of government funding for various things including housing modifications, incontinence products, health care and so on, a number of Delhi parents talked about an assurance of ongoing financial pension from the government to meet the most basic needs of their children when they were not around.

Financial support from the government is good. Most of continence products are supplied etc. and some housing modifications and it’s good that the boys can both get their own money – their benefits…. Respite care, I am glad that that’s a formal support now because I wouldn’t ask my family to do 60 days for Sean, that’s too much. (Barbara, Auckland parent)

The government should give pension[s] so that our kids don’t have to rely on others. (Chitra, Delhi parent)

It’s very important. See if you go and ask someone they will give according to their will, but if it is coming from the government, for example, monthly amount is fixed. That way you know that how much money is going to come and you can plan accordingly. (Gita, Delhi parent)

Many Delhi parents also talked about the role of formal support in the area of home and personal care and felt that the government should provide good residential homes staffed with trained caregivers so that their children could have a place to stay and someone to look after their daily needs.
Very much. Like there are old age homes – there should be residential homes for these kids as well. Currently there is nothing. Many kids are looking for such a place. (Hema, Delhi parent)

When the parents are there they do everything. If the parents are not there then the government must have a [residential] school for them where the kids whose parents are not there can stay there and be looked after there, similar to a hostel where they get food, sleeping facilities and complete care. (Sangeeta, Delhi parent)

Moving beyond the specific areas of support, the parents also identified some other factors that highlighted the broader significance of formal support in their lives. For example, a number of parents commented that having good formal support is significant as it could allow their children to have a good quality of life and it could help the family members to enjoy being just the family without the stress of being a carer.

Around that you put support which is as much to do with for the person as it is with the family so that they can do that other stuff. Because if you don’t put enough support for the family all the humanness and hugging and loving is gone…. Marriages break up – families break up. So if you want to protect who that person is and provide a rich environment for them where they thrive and not be stressed then you need to put the support around. (Judi, Auckland parent)

I feel this is hundred percent significant. The government support is extremely crucial. Through that source our kids can get a lot of things. If the government comes forward then the parents will also feel that there is something for our kids which we can also do. (Sunita, Delhi parent)

**Key informants’ views**

In terms of different support areas, every single key informant from both groups also commented that formal support had a role to play in all the areas of a person’s life. They felt that it differs from family to family as to how involved they want the formal system to be in their children’s lives, but all else failing, the formal support should take the ultimate responsibility to look after the long-term well-being and safety of a person with HCN.
One Delhi key informant highlighted that formal support in the form of day programmes or vocational centres would not only allow the disabled person to have some leisure time or learn vocational skills but could also provide significant respite to the parents or the other full-time carers during the day. The care would then be shared between formal and informal systems and the parents would feel re-energised to provide care for the remaining hours.

One Auckland key informant commented that, ideally, decision making should always remain with the informal support network so that someone outside the system could ensure that right decisions that meet the interests of the person are taken. Similarly, another key informant felt that it would be better to have leisure and recreational support provided by the informal support network as paid services often have a structure that does not work for all people.

Formal support in the leisure area is may be will just make it seem like another part of the programme. It would be less leisurely then. It will become part of the programme – the programme which you have got to live – you know what I mean? Instead of kind of spontaneous and serendipitous, it’s like saying at 9.30 we will have leisure. (Mr M, Auckland key informant)

Thus, the parents and the key informants of both groups considered formal support to be crucial for the long-term well-being of people with HCN. However, they also identified a number of issues with the formal support system which, if not addressed, could have a significant negative impact on the quality of life of the adults with HCN, particularly if their parents were no longer around to advocate for their rights.

**Issues/challenges with formal support**

As discussed in Chapter 4, formal support available to the parents in both countries is significantly different with New Zealand offering a more comprehensive support system covering a variety of services, whereas the Indian system offers minimal support services covering only a few aspects of a person’s life. As a result, the issues and challenges reported by both groups of parents with formal support were also significantly different from each other. Therefore, in this section, the findings from both groups of parents are presented separately.
Auckland parents

Key themes that emerged from the issues and challenges reported by the Auckland parents with formal support are now described.

Disability workforce related issues

The single biggest issue that almost all the Auckland parents touched upon related to the disability workforce as it directly impacted on the quality and consistency of care received by their children. The parents felt that a majority of the support personnel working in the disability sector, including those doing the assessment of the needs, did not have the necessary skills and knowledge to work with disabled people, in particular with those who have HCN. This, in their view, had a negative impact on the quality of care received by their children.

Government talks of their professional carers being better than home carers but that’s a load of rubbish. There are no professional carers. They might be carers paid for by agencies but that doesn’t make them professional carers. (Katie, Auckland parent)

Well I don’t think that they [people with HCN] are getting the skilled quality service that they deserve. (Rosemary, Auckland parent)

The other related issue that the parents talked about included the shortage of staff and a high turnover leading to a lack of consistency in care for their children.

They ring up and say sorry, we haven’t got anybody for you today. We will send in an agency person. I am sorry, no you won’t because they don’t know how to feed him or drive the van. We don’t know if they would know how to communicate. (Holly, Auckland parent)

A majority of the parents, however, did not blame the support workers but rather empathised with them for their situation. The parents believed that the disability service providers and the funding authorities were largely at fault as they often did not value the support workers’ contribution. The support workers were offered very limited training opportunities and were also grossly underpaid with no career path.

There are lots of good people there but it’s a job for them. It’s low paid and low esteemed, so they often move on to other jobs. (Barbara, Auckland parent)
I don’t think a lot of caregivers feel valued. So they don’t value their job. They have work places which aren’t understanding; they really don’t treat them as human beings. I would never expect a carer to be rostered on and work every weekend. They should have a life…. Who in their right mind would think that it’s sustainable. (Louise, Auckland parent)

*Lack of skilled and knowledgeable health professionals*

A number of parents commented that, not only the disability support workers but even the health and fitness professionals, lacked the necessary skills and knowledge to work with people with HCN, especially those with dual diagnosis such as intellectual disability and mental health; or complex medical conditions.

I don’t expect the doctors to know everything but I expect them to find everything out. If you don’t know it, fine – go and find it out. That’s part of your competencies as a medical practitioner to do no harm, and you are not researching the condition you are treating. (Louise, Auckland parent)

*Lack of age and impairment appropriate options*

A few parents felt that both the short-term and long-term accommodation options offered to their children were often not appropriate as they were either placed in facilities designed for older people or were placed with people whose impairments (and hence the support needs) were significantly different to those of their children.

He had three respites where he was put into Alzheimer’s hospital and of course I would bring him home. It wasn’t suitable. There are not many respite places, there are not enough for the population. (Katie, Auckland parent)

I think the health system is making a mistake in putting people with intellectual disability with people with mental health issues. I don’t agree with this and I don’t think it is right. Because Lorraine hasn’t got a malicious bone in her body. She might be a bit rough on a butterfly but everything else she is just absolutely beautiful. (Wendy, Auckland parent)

*Lack of choice and control*

Some parents also felt that the initiatives under the New Model that were designed to offer more choice and control to disabled people and their families did not necessarily give much choice when it came to their children with HCN. According to the parents,
the service providers struggled to meet the high needs of their children for individual care and supervision and as a result operated on an economy of scale basis where a group was the focus of attention as opposed to an individual. Thus, their children were often forced to live at a place or do things which they did not want to.

The government I know they have got certain schemes for getting people into residential care and housing, and choices in community living and all sorts of other things but for the really disabled who can’t make their own decisions, they are not really that practical. They will have to get five people in a five-bedroom residential house to cover the costs and things and you might not be with the people who you want to live with or they might not want to live with you either. (Barbara, Auckland parent)

Places have promised us one to one [care] that yes we will get her out of the chair and walk her, yes we will do this and that but it’s a lip service – doesn’t happen. She ends up sitting in that chair for hours and hours in the end. (Louise, Auckland parent)

Inadequate and non-flexible funding

A few parents mentioned that the funding received by their children often fell short when it came to meeting their additional disability related needs and participating in community based activities and hence they had to top up a significant amount from their own pockets. Some parents also felt that the funding system was too regimented and offered little flexibility on what the funding could be used for.

You know it’s meant to be about inclusive community life but it doesn’t necessarily translate to that because a person doesn’t normally have a source of income therefore they don’t have the income for those things and that usually falls on the family. (Judi, Auckland parent)

The issue that I have with government funding, I guess, is that it’s probably sort of designed by a hard and fast rule book and it’s not flexible enough to cope with many, many different scenarios. I think there does need to be a lot more targeted support rather than OK, you tick the box – you are disabled so you get this. (Russell, Auckland parent)
**Fragmented, complex and inconsistent support system**

Many parents also found the formal support system to be too complex to navigate with multiple agencies involved in funding the different services. The parents also referred to the issue of disparity between the funding received by the people funded through different agencies – for example, those funded through the ACC received much higher funding than those funded through the MoH.

But the only difficult part is that when it is so horribly fragmented and there is so much red tape that afterwards it’s overwhelming for the parents to try and work out what they are meant to do. (Joanna, Auckland parent)

I have a big bugbear and I am sure anybody does who is MoH funded that there should be such a big discrepancy between the funding for a child or adult with the same disability between ACC and MoH. (Tania, Auckland parent)

Louise talked about her first-hand experience of such fragmented systems where she could not get appropriate funding either from the MoH or from the DHB as her daughter had a very complex medical condition.

I can’t be with her 24x7, I can’t do night shift, morning shift, afternoon shift, evening shift. I can’t do three to four shifts a day, it’s unsustainable; and yet I am expected to because she doesn’t fit into either funding stream because she was born with [names daughter’s rare medical condition]. (Louise, Auckland parent)

**Little consideration of family situation**

Finally, many parents felt that the government had limited understanding of, and little consideration for, the parents’ situation and expected too much from them. The parents talked about having to put in a lot of extra hours to cover for the times when care was not funded or having to manage the finances and care operation for their children when funded through the individualised funding system.

Well we are getting tired of having to do everything. We would like – it would be good if the government relied a little bit less on us and gave us more than just [a few] hours of support. (Donna, Auckland parent)

It’s almost like wow, you expect us to be brilliant at everything all the time and that’s our support. So although it’s financial support and in the bigger picture it
ends up being support, there is this giant expectation that you have to hold it
together and that’s incredibly difficult. (Joanna, Auckland parent)

One parent suggested that, due to a lack of monitoring and accountability, even the
monitoring of the quality of services often landed up on the parents. This, in her view,
was not an ideal situation as even if the parents observed instances of poor service, they
were often too tired to make a complaint about it and as a result the problem persisted.

I think that at the end of the day, services like NASCs and DHB they know we
are too tired to complain. They have got away and particularly the service
providers have got away with a huge lot of stuff that goes on there because they
know that we are too tired to complain. They know that we say we are going to
go to HDC but we don’t because it’s too tiring. (Louise, Auckland parent)

Thus, as highlighted by the findings in this section, many Auckland parents were of the
view that the formal support was falling short of adequately meeting the support needs
of their adult children with HCN.

Delhi parents
The key issues identified by the Delhi parents with the Indian formal support system are
now described below.

Minimal or non-existent financial support
According to the parents, the biggest issue was the lack of financial support for disabled
people and their families. Many parents mentioned that the benefit allocated in the form
of pension was not available for all disabled people in all the regions and even where it
was available, the amount was hugely inadequate to meet even their basic needs.

And the biggest fault with our government is that in just ₹1,500 [little over NZ
$30] per month how can – if I die today, how will they be able to even eat their
food in ₹1,500? So the government should think about them. (Radhika, Delhi
parent)

Bribery and corruption
Another major issue identified by a majority of the Delhi parents with the formal
support system was bribery, corruption and a lack of commitment on the part of the
government. The parents talked about having to bribe the government officials to get
what they were entitled for. They mentioned that even the disability organisations had to bribe the government officials to get their funding grants.

I came to know that they do get pensions, I have been trying to get that for last three years but we haven’t got anything yet. I don’t know what’s the problem. I have submitted so many forms but nothing happened. If I bribe somebody ₹2,000 I think his pension will start. That’s the system. (Hema, Delhi parent)

Because they [the NGOs] also have to give bribe[s] – they don’t get the aid without that. So for such kids it is really crucial that there should be some form of monitoring or vigilance of all such schools [disability organisations] to see what’s happening with the kids. (Mr Shah, Delhi parent)

Further, the parents believed that a significant proportion of the funds allocated for disabled people or disability organisations never reached its rightful recipients and got “eaten up” by the officials acting as the gatekeepers of those funds. Similarly, many parents were of the view that the government showed a lot of schemes and services for disabled people on paper but often they were not provided on the ground.

I don’t trust the government body to run any programme efficiently and to the best of it. There is a lot of slack, there is a lot of inefficiency, there is a lot of unknown accountability, there is a huge amount of lethargy in implementing anything that may seem rosy on paper but I don’t trust government programmes running well. (Kanchan, Delhi parent)

*Lack of suitable residential homes*

Many parents expressed their frustrations over a lack of appropriate residential homes for their children. They mentioned that there were not too many private options and the living conditions in the state-run homes were appalling. The quality of care provided in the state-run homes was also of a poor standard due to lack of skills, lack of disability-specific knowledge, and the wrong attitude amongst the support workers working in those homes.

The fact is that the state will always have shitty options in which you will never put your child and I hope to God that she never has to go into a current state-run home or a ghastly thing like that…. Ok, we have to do something so let’s do it kind of attitude. It’s not – hey, these guys are great, they can do wonders, they
deserve the best…. It’s that attitude of pity that needs to get away. These people don’t need pity – they need equality. They need to stand on the same platform as anybody. (Manju, Delhi parent)

*Lack of suitable day centres and community based activities*
Some parents mentioned that there were also limited options when it came to suitable leisure and recreation programmes or vocational activities for their children. Further, where such facilities were provided by the NGOs, they were often not funded or inadequately funded and hence they were forced to charge a fee which many families could not afford.

I also couldn’t find any other such place similar to a music centre for normal kids. (Hema, Delhi parent)

I just found out about this school so I have started to send him here. I didn’t send him earlier because I was scared from where will I get so much money. You need to pay a lot for their admission – like ₹4,000 to 6,000. Now do we eat food or pay such fees. (Mahesh, Delhi parent)

A couple of parents also raised some concerns with the quality of care received by their children at the day centres.

Sometimes our kids are handed over to such people for care who don’t even know how to clean their private parts properly. I wish that these people should be properly trained in how to toilet our kids. But that doesn’t happen in any organisation including where she goes now. Staff should be trained in toileting kids. (Sunita, Delhi parent)

*Inaccessible health care and administrative services*
In the area of health care, the biggest issue faced by the parents was that to access free health care in the government hospitals they had to travel long distances and/or wait in long queues to receive treatment for their children. This caused a lot of difficulties for them as their children often got irritated with such long waits.

There are free services but they are so crowded that at times there is [a] waiting period of a couple of hours and you have to wait in long queues which these kids can’t do…. We think that rather than wasting time in travelling and waiting there
and plus bear the travel expense to the government hospital and back it’s better just to pay the fees and go close by. (Sangeeta, Delhi parent)

When we take our child to the hospital, they don’t even let us in till our turn comes as they know that the child would cause trouble. There should be a system where they understand that because this child has a problem let’s take them in first. (Nita, Delhi parent)

Similar issues were raised in accessing administrative services such as getting the assessment of their children’s disability done and getting a disability certificate that would allow them free access to certain government-run services such as public transport and health care.

Even for [the] certificate, we had to go to a particular hospital. They make you run from one place to another. We have to go around everywhere with the child. Why can’t they send a team at the school where these kids are studying? (Mr Sharma, Delhi parent)

**Key informants’ views**

A majority of the issues and challenges with the formal support system as identified by the key informants from both groups were very similar to those raised by the parents. A couple of Auckland key informants, however, commented that a total reliance on formal support could make people with HCN more vulnerable and, in turn, it could have a negative impact on the overall quality of their life.

I think in just about all cases, the quality of life would diminish in those settings. And I don’t think people have the choice or the ability to communicate their choices and so their needs tend to become marginalised in those paid environments. (Mr I, Auckland key informant)

One Delhi key informant who runs her own disability NGO suggested that the government support that they got in terms of funding covered a very small portion of their operational cost. Further, to get that funding they had to go through a highly bureaucratic process involving a lot of paperwork and as a result they stopped seeking government funding and were more reliant on private donations.
Improving access to formal support

The parents also gave a number of recommendations on how formal support could be improved for people with HCN and their families. Key recommendations include:

*Provide more funding and more flexibility in its use*

Many parents from both groups suggested that the government should provide more funding that could be used in more flexible ways, and to allocate funding based on the assessment of type of disability and related support needs rather than applying a standard rule across all disabilities.

So their protection I guess is that you test for and you get that group and you give them what they need to participate and not dilute the money down all the time…. So a certain percentage of it - ten or twenty - could be spent on extras to enable the life plan to happen. (Judi, Auckland parent)

Yes, they do have higher needs…. If someone else is going to a doctor, they will go to a doctor who will be least expensive. Whereas, with these kids we will think about taking them to the closest doctor whether he is cheap or expensive because we can’t travel far with these kids. So in all areas these kids have high expenses. (Sangeeta, Delhi parent)

Either they take these kids to a level where they can have their own means of earning and, if they can’t do that, then they should give some monthly income so that their needs can be met comfortably. (Radha, Delhi parent)

A couple of Delhi parents also suggested that the funding should be provided based on the socio-economic background of the parents.

But the thing is that there should be such centres from the government that are free. Even if there is a charge, it should be either very minimal so that everyone can afford to pay it or charge people according to their own affordability. Because the families like ours can manage it but how will the poor people do it? (Mr Sethi, Delhi parent)

*Improve quality of workforce*

In relation to improving the quality of workforce, the suggestions given by the parents included providing higher wages and a career path to support workers and providing them with the necessary skills and training to work with people with HCN.
So I think it needs to be a well-paid job and it needs to have a career path where the person is valued and they get some skills. (Judi, Auckland parent)

I would like to see that there be a specific qualification for very high complex needs because I don’t think that the qualifications that are out there at the moment are applicable or reach the level of expertise that’s needed to care for non-verbal high[ly] complex [people]. (Louise, Auckland parent)

Yes, the level of care that we expect will not happen if there are no trained staff. (Sunita, Delhi parent)

*Provide for better monitoring and improved accountability*

Many parents also suggested incorporating better accountability provisions for both the service providers and the parents managing funds on their children’s behalf.

And yes, that’s one of my wishes is that there should be accountability for neglect and abuse cases from professional services. There has got to be some accountability. Ahh [gets a bright idea] – that’s what we need – spot checks! No notice – no nothing … I think that would help a lot. (Wendy, Auckland parent)

I don’t think it’s a good idea to give families a whole pile of money with no strings attached or no safety guard. I like the system of they give the amount of money, you have got the year to spend it and these are the criteria. (Judi, Auckland parent)

First and foremost, the role of the government is to monitor the schools and other centres they are funding. Go there and find out what they are doing. Ask them that you are taking funding from the government – what are you doing with it? There are so many places that just remove the kids whenever they feel like. They might just say stop coming from tomorrow. So there is no monitoring – nothing. (Mr Shah, Delhi parent)

*Provide better employment and vocational opportunities*

One Auckland parent and many Delhi parents felt that the government should work towards creating more jobs for disabled people or help them set up small businesses so that they could be self-reliant and at the same time contribute back to the community and feel valued by the society.
If you are disabled and you are able to have an occupation you immediately feel very important and valued which helps you get better self-esteem, your health gets better, you have people around and you are not isolated. So that is all positive and positive and positive. (Joanna, Auckland parent)

At least for some smaller jobs these kids should be considered. If not full time, offer them part time jobs. That’s when they will be able to move ahead in the society. (Radhika, Delhi parent)

Every [government] department should adopt a disabled child. They can employ disabled people in jobs according to their ability and pay them accordingly. Somebody might be employed to clean tables, somebody can be given a job to give forms to people as they come in and so on. (Mr Sharma, Delhi parent)

One Delhi parent also suggested that such centres should be available in local communities so that people do not have to spend too much time and money in travelling.

*Provide one-stop shop for all administrative services*

To assist the families of disabled people navigate the formal support system with ease, one Auckland parent suggested providing one central point of contact who could manage all the services for the child:

I really think that instead of it being so fragmented there needs to be a holistic quality of life manager in the lives of people with disabilities and I think one day it will get there. It’s like this local area coordinator thing. That sort of concept. (Louise, Auckland parent)

Similarly, many Delhi parents felt strongly that any government formalities that the families were required to complete should be organised in their local community and done on a priority basis so that the families did not have to travel a long distance and wait in long queues. Some parents also suggested that such formalities should be done at a centre that the child already attended or at a facility close to the child’s home.

They should meet us at a place where our kids are comfortable. They should not treat our kids like other kids and ask them to wait in a long queue. If there are disabled kids, they don’t have patience to wait for long time. They shouldn’t be asked to wait. (Sunita, Delhi parent)
Work in partnership with parents

Finally, the parents felt a very strong need for the government to work in partnership with the parents. Also, for that partnership to work properly, they suggested that the government should listen to what disabled people and their parents had to say, work closely with the parents in designing services, and provide professional support to the parents in working with the system.

I think they have got to listen to what the disabled people want. Because they haven’t been doing it and until they listen – really listen, and react to what they hear [shook head to suggest that they will not get it right]. (Katie, Auckland parent)

Key informants’ views

Whilst many of the suggestions given by the key informants on how formal support could be improved for people with HCN were similar to those given by the parents, they also gave a number of other recommendations as listed here.

Forward planning

The parents and professionals need to talk to each other at an earlier stage about long-term support for the person rather than waiting till it reaches a crisis point.

I think service designs could be better. I think we have a system that’s built around crisis and I think the future is about families and providers thinking through the needs of individuals before crisis. (Mr I, Auckland key informant)

Change mentality from “welfare” approach to “investment” approach

One Auckland key informant suggested that providing formal support is about investing in someone’s quality of life because, in the long term, the care becomes less expensive as either the person lives a happier and healthier life or becomes a contributing member of society.

Sensitise professionals and policy makers

Some key informants felt that the people making the decisions that affect the lives of people with HCN needed to understand and appreciate the unique situation of each family and learn from the parents and the NGOs about how to deliver services. One Delhi key informant even suggested that the government should remove itself from the operation of the services and provide necessary support to the NGOs.
Formal support – general remarks

While discussing the significance of formal support, a number of parents talked about the impact it has on their own mental and physical health of looking after an adult child with HCN.

It’s quite stressful living with someone with a severe disability all the time. (Judi, Auckland parent)

My worst nightmare is my wife dying. I just don’t know how I would cope. It would be like falling off a cliff as far as I am concerned. It would be very, very difficult. (Russell, Auckland parent)

It’s getting to a stage now where my husband has got a bit of a back problem lifting him and we have always avoided getting ramps, having specialist vehicles, getting lifting things in the house, because all of that makes us disabled as well. (Tania, Auckland parent)

I know what happens in India is family, family, family. Parents are only starting the institutes, parents only are leaving their lives to get things done, parents only are fighting with the government – then parents have no life left? Where is the life of the parents? It’s not there. Either you fight or you earn or you take care of family. And the family is not only having this disabled child it’s also having other siblings. That is the reason it becomes more challenging. (Shobha, Delhi parent)

Even parents get bored and frustrated because after all there is a limit to everyone’s ability to cope with a person. When the person is at home 24x7 then that limit reaches very fast. (Ms Sethi, Delhi parent)

Therefore, many Auckland parents were very grateful for the level of formal support they were receiving and admitted that it would have been difficult for them to manage their children’s care without that support.

I am immensely grateful for what we get. Certainly, we couldn’t manage without it. We would be financially strapped without it. So it has been a huge bonus for our family to have that. (Russell, Auckland parent)
We could not have survived without some of the organisations that provide leisure activities for such people as Maria to have holidays away from their parents. (Mrs Smith, Auckland parent)

In New Zealand we have got very comprehensive disability support really to a greater or less extent. Some are not ideal but making comparisons to other environments or other countries we do have a very comprehensive system. In terms of rights of disabled people, it’s a good backbone for the provision of a good life for a person with a disability. So it’s good to have that structure in place. (Lesley, Auckland parent)

A couple of Delhi parents, too, expressed their satisfaction with whatever little the government was doing and they also understood the limitations to what the government could do given the sheer size of the disability population in India.

That is difficult. It’s not possible for the government to provide individual help to every child in his or her own house. At max they can set aside a fixed sum per month for such kids so that the parents who are needy will know that at least I am likely to get ₹2000 per month so I can do something for the child. (Ms Sethi, Delhi parent)

**Key informants’ views**

The key informants also made a couple of very useful general remarks in relation to formal support. For example, one Auckland key informant asserted that formal support should not be viewed as a handout to the families of disabled people but as a compensation for our society’s discriminatory structures. One Delhi key informant, on the other hand, defending the government suggested that it is difficult to meet all the needs of a person with HCN through formal system as there are various competing deserving groups reliant on the limited pool of government funding.

The next section presents my findings on the parents’ views on the attitude of the general public and the state towards disability and disabled people.

**6.3.6 Public attitude**

The definition of “informal support” used for the purpose of this study includes the support the families receive from the wider community in addition to their family and friends. To get a better understanding of the factors influencing the role of the
community in the lives of disabled people and their families, the parents were asked to share their views and/or experiences concerning the society’s attitude towards their children in particular and disability in general. This section presents the information provided by the parents in response to the question – *How disability or disabled people in general, are viewed in the community that you belong to?* As sub-questions to this main question, the parents were also asked to share their views on the government’s attitude towards disabled people; and the likely impact of the attitude of the community and the state on their children’s future support needs. Accordingly, the responses of both groups of parents are presented below under three separate sub-sections entitled “Societal attitude”, “Government attitude” and “Attitudinal impact.”

**Societal attitude**

A number of parents from both groups commented that, when it came to their attitude towards disability and disabled people, by and large, the society offered a mixed bag – it had both kinds of people – those who accept it and those who do not. They felt that the society had become more accepting of disabled people, especially over the last couple of decades, due to increased awareness amongst the general public and the emphasis on mainstream education.

> I think there is a big difference in a positive way from the last decade to this decade. I think there has been a lot more awareness created out there and a lot more understanding and some empathy. It’s a big difference. (Wendy, Auckland parent)

> I think mostly people think good about disabled people … and want to help them. (Mahesh, Delhi parent)

The parents also talked about cultural and gender differences in acceptance of disability. They commented that some cultures were more accepting of disability than others; and the younger generation was more accepting than the older generation due to their exposure to disabled people in their schools and community. Judi summarised this point very aptly:

> I think it depends on, if it’s an older generation or someone over 40, and they have had a lot of experience with exclusion then you can’t change their views. They have no human experience with person with a disability. When you get younger people who have had a lot to do with integration at school or within...
their families especially with autism because it’s on the rise and there are a lot more autistic people around then it’s a very easy bridge. It’s nice. People are very courteous, people are fine, people kind of get [it]. So it’s very much to do, as I find, is with person’s age and culture. (Judi, Auckland parent)

However, a few Auckland parents and many Delhi parents felt that there was still a lot of ignorance and lack of awareness leading to a lack of societal acceptance of disabled people.

I think people in general just accept but with a “but.” I don’t think that people really go out of their way to include and they are still – even though attitudes are changing, they still see us as different – them and us. (Donna, Auckland parent)

I still think there is huge prejudice. There is big, big fear of disabled people. They talk down to them, that’s the other thing that I find really hard. (Holly, Auckland parent)

No, it [the acceptance] is not there. I just feel that now I am raising these kids on my own but after I go how will the society treat them? I just don’t understand. (Radhika, Delhi parent)

Not much [acceptance]. This country is not good for disabled people. It doesn’t care about – it doesn’t think of the disabled people at all. Because we are so many people. There is no regard for a human life in this country. So where is the place for them? (Manju, Delhi parent)

In the experience of both groups of parents, the attitude of the public towards their children included prejudice or disapproval (expressed through strange stares or avoidance); pity or sympathy; patronising or disrespectful attitudes; or in some extreme cases, the use of insulting or abusive language.

A couple of Auckland parents suggested that even some disabled people themselves did not understand the needs of those with HCN.

Inside disability I don’t even think that what I call “able disabled” have a good understanding always of what having a very high complex disability means to everyday life and yet it is those able disabled people that are on reference groups that are involved in advocacy. (Louise, Auckland parent)
According to many Delhi parents, people expressed their lack of awareness in a number of ways including asking weird questions such as why their child was disabled or when would their child become alright; or by using inappropriate language – for example, calling an intellectually disabled person *paagal* (mad); or by asking parents to take their child for some ancient treatment to cure their disability; and so on.

If someone just looks once it’s fine no one feels bad about it. But when they talk it hurts. For example, they talk amongst each other that there is something wrong with this child’s brain. He is mad. People use the word mad a lot. In India even blind people are called mad. So that affects us a lot. (Gita, Delhi parent)

A majority of the Delhi parent participants belonged to the Hindu community. They mentioned that even today, many people of their community believed that disability happens due to the sins of the past life. They believed that being born with a disability or having a child with a disability was a punishment for one’s sinful *karmas* [deeds] in a past life. Due to such beliefs, their attitude in general was not very helpful. Only one person suggested that the Hindus had a caring attitude but that too was primarily from a sympathetic and charity viewpoint.

Their thought is that this is some *upari hawa* [evil power] or this is a fault of the ancestors. They don’t believe that this is a medical problem, they just think that this is a result of the sins of the ancestors and these kids are getting punished for that; or they are paying for the sins of their own deed in the previous birth; or you must have done something wrong as a result your kids are like this and so on. So the Hindu community thinks like this. (Radhika, Delhi parent)

One parent suggested that in rural India the ignorance was very high and there was still a great stigma attached to having a child with a disability and some people even believed that disabled people had no right to live.

Many parents from both groups whilst discussing the attitude of the society, also expressed their views on what could be done to improve societal attitudes. Their suggestions for improving attitudes are now discussed below.

*Improving societal attitudes*

A number of parents felt that the best way to improve societal attitude towards disabled people was for the families of disabled people themselves to play an active role in
educating the society. They believed that how they approached people in the community and their own attitude and behaviour when out in public would determine how people react to them; and that in turn, could influence societal acceptance or otherwise.

I think we as disabled families can do just as much for the public as expecting it back, yeah. Because we have the benefit of knowing our people. They don’t know our people, they don’t know how to react. (Louise, Auckland parent)

I have noted that this depends on you. If your behaviour towards Jitesh is wrong, the people are also going to look at him in similar manner. If you are looking at Jitesh in a nice manner and showing your affection towards him even in front of the public, then people’s attitude also changes accordingly. (Hema, Delhi parent)

We go to pools and [the] more times we are out there, [the] more people we are educating. And maybe softening a few hearts out there too. (Wendy, Auckland parent)

So we are doing a lot of work as parents. We do a lot of advocacy, one and the second is that because these malls have come up we do these flash mobs kind of shows where we are doing things with all our children and all of us are dancing and there is a lot of education. It’s all happening. (Kanchan, Delhi parent)

Many parents from both groups also talked about the potentially significant role of the media and a partnership between the government and the NGOs in raising community awareness. However, a couple of Auckland parents suggested adopting a cautious approach as, in their views, people could not be forced to accept disability.

And I feel that way about disability is that let’s not shove it in people’s faces but let’s just take it as a matter of fact and part of life. (Russell, Auckland parent)

You can’t force communities to be accepting of people with disabilities for example. It’s a human nature thing, it’s a choice and it’s about making a right choice or being raised in an environment where disability and difference is accepted. It’s an evolution – we are still undergoing that evolution. (Lesley, Auckland parent)
**Key Informants’ views**

The views of the key informants from both groups were similar to those expressed by the parents in suggesting that the attitude of the society towards disabled people was changing for better but there was a long way to go. The key informants also talked about the cultural and age differences in acceptance of disability and disabled people.

**Government attitude**

When asked to talk about the government’s attitude towards disability and disabled people, the responses of the Auckland parents in particular, were full of anger and frustration. They felt that the government considered disabled people as a cost to the economy; the government did not value disabled people or care about what disabled people and their families had to say; and that there was a lack of understanding of disability on the part of the officials making decisions and as a result they provided more lip service than any real support.

I believe the government wishes they weren’t around [laughs sarcastically].
(Holly, Auckland parent)

The government’s view is that disabled people don’t contribute, so they are the least valued people in the system. They also take, need, use lots of government funding so they are seen as the drain on the economy and they are not contributing back again. (Joanna, Auckland parent)

Bad [laughs sarcastically]. Well they just throw peanuts and tell us to make do with what you have got. They don’t want to hear from us. They give us a little bit to try to keep us happy but they are not supporting, they are not listening for a start and they are not putting enough money in the right place. But talking about attitude, I think there is disabled person and there is a parent, and they certainly treat the parents like shit. They probably treat the disabled people better than they treat the parents because they are relying on us to do everything for nothing. There is more access and less barriers in New Zealand but as long as disabled people and their families are not included or are not at the heart of all policies then disabled people and their families are not equal members of societies.
(Donna, Auckland parent)
Thus, by and large, the Auckland parents felt that the government had a very negative attitude towards disabled people and their families. Only one Auckland parent felt that the government’s attitude was positive and supportive.

Delhi parents, on the other hand, were largely divided in their views on government attitude. There were many who felt that the government’s attitude was negative and they provided only lip service; however, there were also many others who felt that the government had a positive attitude and tried to do whatever it could within its limited means.

Very basic attitude is that you are not considered as a citizen. (Shobha, Delhi parent)

They [the government officials] don’t want to know because they don’t care and if they know then they have to do something about it. It’s easier not knowing. (Manju, Delhi parent)

Government is trying – they give pension[s] as well. So they are doing good. Their attitude is good that’s why they are helping so much. They understand that the kids need so much that’s why they are giving passes to the kids, issuing disability certificates, etc. All this is done by government only otherwise who else will do that. (Reshma, Delhi parent)

The government does a lot but not at the level that people need. There is not enough facility. (Gita, Delhi parent)

Key informants’ views
Every single Auckland key informant also commented that the attitude of the state towards disabled people was not very positive and it needed to change. The key informants were of the view that the state did not understand the disability population well; the policy structures were not responsive to their needs; and in general, the disability sector got a raw deal in number of aspects as compared to some other sectors.

Disability is kind of like Cinderella of services and all the other kind of services attract a lot more funding and there is a lot more tolerance for lower funding and lower quality services. (Ms H, Auckland key informant)
Similar to the Delhi parents, the Delhi key informants were also divided on their views on the state attitude towards disabled people and expressed a mix of positive and negative reactions.

**Attitudinal impact**

The parents were also asked to talk about their views on the impact the attitude of the society and the state might have on their children receiving the supports necessary for their long-term well-being.

Many parents felt that the government’s view of disabled people as a cost to the economy had a negative influence on their decisions around the amount of funding given to the sector and if such an attitude continued, it could have a significantly deteriorating impact on the quality of life of their children.

The fact that they always have that power over you, they can actually cut your funding. These guys’ world are in their hands. They are like Gods. They play Gods with our kids’ lives really. That’s a worry. (Louise, Auckland parent)

If the government provides facilities, why won’t we do things for our kids but it becomes very difficult when there is no support, we can’t do things even if we wish. To take them around somewhere often parents don’t have enough money for auto and as a result they keep their kids at home and don’t even send them to schools [day centres]. (Sunita, Delhi parent)

Some Auckland parents were also concerned that due to a lack of knowledge and understanding on the officials’ part of severe disabilities and how it impacted on people, the funding allocated to people with HCN was often not sufficient to meet their additional specific support needs and this, in turn, could potentially create safety issues for their children going forward.

Because funding for service providers comes from the government and the government is not consulting the right people and they are not following their actions then they are not getting a proper picture and then they are not going to put the proper funding where it’s required so it could mean that Lorraine wouldn’t get the services she requires and she could suffer and it could be a bad situation for her. (Wendy, Auckland parent)

Talking about the impact of societal attitudes, the parents of both groups felt that it had a
significant impact on a disabled person’s social life as they were either unable to access community facilities or did not go out to avoid rejection.

Yea, I mean if the community thought that the disabled people should be locked away and never seen, I wouldn’t take them out so much or think that they might be better off in their own place. (Barbara, Auckland parent)

The impact is that most of the parents don’t feel like taking them out. If they have to go to any function or whatever, they just think that it’s better to keep the child at home as otherwise people are going to make [them] a laughing stock. He will just become a display object and people would look with strange eyes. (Mr Shah, Delhi parent)

Some Delhi parents also pointed out that the negative attitude of the society and the state did not only impact on disabled people but also created negative outcomes for the entire family. A lack of acceptance made the parents feel either isolated or helpless.

The society will have to change their attitude towards these children. This will have to begin right now or else in the coming days, these kids’ future will be very dark. My husband was saying that either these kids should be self-dependent or while we are still alive the God should take them away. We sometimes think like that – why? Why such thoughts come in parents’ minds? Looking at the society and because we don’t get any support from the government, so out of despair. (Radhika, Delhi parent)

One Delhi parent, however, expressed a lot of hope and confidence that, in future, things would change for better for disabled people and their families.

But I am sure that even that will change. There will be much respect for them and then there will be jobs and the government will also take care of that with the disability bill and various financial policies. There has to be and we are working very hard for this and I hope that there will be a change and there should be. (Monica, Delhi parent)

Key informants’ views
The key informants also felt that the negative attitudes of society and the state could have an adverse impact on the overall quality of life of disabled people. In addition,
according to the key informants, disabled people also faced a lot of discrimination in society and were deprived of vocational and employment opportunities.

One Delhi key informant alerted that inappropriate awareness raising could lead to exclusion and inequality as people then tend to operate from a charity model. She felt that people often purchase the products made by disabled people with the mind-set of helping a poor disabled person irrespective of the quality of the product.

See this is real life, so you can’t have one and not the other. So if you constantly talk about the care and support and charity and money that you have to donate then you are not looking at equality. So that has led to what we should give to a poor disabled person…. Aid and charity does not lead to or will ever lead to any degree of equality. (Ms D, Delhi key informant)

In summary, the parents as well as the key informants felt that the attitude of the society and the state needed to improve for people with HCN to be able to participate in the community on an equal basis with the others.

6.3.7 “Most important” responses
Towards the end of each interview, the parents were presented with a paper that listed the four sub-questions of the final interview question. They were asked to talk about:

1. Three most important changes they wanted to see happen during their lifetime that would help them die peacefully in regard to their children’s future
2. Three most important suggestions they had for the policy makers/funders
3. Three most important suggestions they had for the other parents
4. Three most important people in their child’s life besides them

Many parents found this to be the most sensitive question to answer and often gave very emotional responses, particularly to sub-question 1. As mentioned in the Methodology chapter, giving the parents a chance to look at this question prior to answering and having a brief break to think of the answers did help to a great extent in reducing some of the sensitivity around this question.

During the data analysis stage, for both groups of parents, all the responses given by the parents under each sub-question were compiled in a list. The list was then sorted in the order of how many parents gave a particular response and thus the top three responses for each sub-question were derived for each group of parents. In the sub-sections that
follow, the three most common responses given by the parents of each group are presented first in a table; a combined list of the other responses given by the parents from both groups follows the discussion of the table items.

Changes that would help parents die peacefully

As discussed earlier in the “Desired changes” section of this chapter, the parents talked about a number of changes that they felt were necessary for their wishes to come true and to alleviate some of their worries. This section, however, summarises the responses of the parents when they were specifically asked to list the three most important changes they wanted to see happen during their lifetime that would help them die without worries.

The three most common responses given by both groups of parents are presented below in Table 2. The final column shows how many parents gave a particular response.

Table 2.

<table>
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<tr>
<th>Changes that would help the parents die peacefully</th>
<th>Auckland Parents – Top Three Responses</th>
<th>(n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Find someone who can take over the care/oversight of care of their child</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>2 Sort out the living arrangements for the child</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>3 Assurance that the child will be able to live the life of his or her choice</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Delhi Parents – Top Three Responses</th>
<th>(n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Find someone who can take over the care/oversight of care of their child</td>
<td>8</td>
</tr>
<tr>
<td>2 Sort out the living arrangements for the child</td>
<td>7</td>
</tr>
<tr>
<td>3 Child becomes independent in self-care and managing personal affairs</td>
<td>5</td>
</tr>
</tbody>
</table>

As can be seen from Table 2, for nearly half the parents from both groups, the most important change they wanted to see happen was to find a person or an agency that could take over from them their existing caring role and/or the role of overseeing the care provided by the formal system. While some parents had no idea about who that someone could be, the others talked about the potential role of other family members, a trust, a team of guardians, an individual professional, or an organisation in taking over the caring role from them.
Yes, there should be someone to whom we can go and pass it on to, say this is what needs to happen when we are no longer here. (Donna, Auckland parent)

I would like to see Maxine maintain control over service provision and to meet the needs for her care under the guardianship of the shared guardianship team. (Louise, Auckland parent)

First, the biggest things is that there should be someone – either through a government or an organisation’s support – who will look after my child well. (Sunita, Delhi parent)

That his brother gives us assurance that you don’t worry, I will take care of him. (Nita, Delhi parent)

Over one-third of parents from both groups mentioned that it was important for their peace of mind to find a place where their child could live a safe, comfortable and happy life after the parents were no longer alive. Again, whilst some parents had some idea about what that living arrangement would look like, the others were not so sure about it.

That we have fully settled him into a group home, where he is loved. (Holly, Auckland parent)

That I knew that there was a place where if we did die before him or couldn’t look after him that I would feel comfortable about him going to. (Tania, Auckland parent)

Definitely I will be more in peace when I die if I see her happily living with my son’s family. (Shobha, Delhi parent)

First, the biggest thing is as I said before, there should be an organisation where our kids can stay safely after us. So that we can think that after us, our kids will be able to live here. They should start going there whilst we are still alive so we can be reassured that after us our child will live here for [their] lifetime. (Sangeeta, Delhi parent)

The third most important change that the Auckland parents wished for was an assurance that their child will be able to live a life doing things that they like. Thus, to be worry free about their children’s future after them, a consideration of their children’s likes and dislikes in how future supports are delivered was very important for these parents.
He is respected and he is living a life that he wants to live. Guarantees around his support that he would be supported the way he wants to. (Donna, Auckland parent)

Seeing their child become independent in managing their own personal care, health or financial affairs was the third top response from the Delhi parents. They talked about their child being “self-dependent”, “successful”, “cognitively able”, “alright”, or even “fully cured” so that they can manage their own affairs.

One is I would like to see that Jitesh becomes alright. If not, at least he should be self-reliant like in the areas of personal care and household work. (Hema, Delhi parent)

The following is the list of the other changes that the parents wanted to see happen during their lifetime. The list below does not follow any particular order and includes the changes talked about by both groups of parents.

- Assurance that the child will be safeguarded and protected
- To have a qualified disability workforce that can work with high needs
- To have health professionals who understand the medical conditions of their children
- Government recognition of specific needs of people with HCN
- Secure child’s financial future
- That the child gets married
- That the child dies before them

**Suggestions for the policy makers/funders**

As discussed earlier in the Formal support section of this chapter, the parents gave a number of suggestions on how the delivery of the formal support services could be improved to better serve the future needs of their children. Many of these suggestions were targeted towards the policy makers and/or funding bodies. This section, however, summarises the responses of the parents when they were specifically asked to list the three most important suggestions they had for the policy makers and/or funders for improving the lives of the people with HCN whose parents are no longer there.
Table 3.

*Three Most Important Suggestions for the Policy makers/Funders*

<table>
<thead>
<tr>
<th>Suggestions for policy makers/funders</th>
<th>Auckland Parents – Top Three Responses</th>
<th>(n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Provide more funding to cover specific support needs of people with HCN</td>
<td>7</td>
</tr>
<tr>
<td>2</td>
<td>Listen to what the disabled people and their families have to say – walk in their shoes</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>Improve quality of disability workforce – provide better training, higher wages and a better career path for the support workers</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Suggestions for policy makers/funders</th>
<th>Delhi Parents – Top Three Responses</th>
<th>(n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Provide good quality residential homes</td>
<td>8</td>
</tr>
<tr>
<td>2</td>
<td>Provide financial help to disabled people</td>
<td>8</td>
</tr>
<tr>
<td>3</td>
<td>Provide vocational or employment support to disabled people</td>
<td>5</td>
</tr>
</tbody>
</table>

The suggestion to provide more funding to cover specific support needs of the people with HCN was given by half of the Auckland parents.

> We are not all the same and that’s something they need to understand that not all disabled people have the same needs or parents. (Holly, Auckland parent)

> Providing appropriate funding – I have never thought that there is not enough funding in the sector, I just think that it’s wrongly administered. (Rosemary, Auckland parent)

Another suggestion that five Auckland parents had for the policy makers and/or funders was to listen to them and their children when making decisions affecting their lives. These parents felt that the policy makers needed to walk in their shoes to get a better understanding and appreciation of their situation.

> Listen to the parent voice – the parents of the severely disabled people because our children can’t have a voice, so we have to be the closest thing to their voice. (Barbara, Auckland parent)
I think we should get a policy maker or funders to spend a week in a care facility or in a parent’s home and walk the mile as those other parents have. (Wendy, Auckland parent)

The third most important suggestion that the Auckland parents had for the policy makers was to work towards improving the quality of the disability workforce. The parents felt that a lack of training, inadequate remuneration, and a lack of career path were the biggest hurdles in attracting and retaining good support workers and that the policy makers needed to address this matter urgently.

But for that they [disability support workers] are not gonna work for $20 per hour – so they need a financial career path based on experience and academic skills leading to some sort of supervisory role. (Judi, Auckland parent)

The top three suggestions given by the Delhi parents were different from those given by the Auckland parents. One of the top suggestions for the policy makers and funders provided by nearly half the Delhi parents was around providing more residential homes for their children. These parents talked about having homes where all the other needs of their children could be adequately met and where their children could live a happy and comfortable life.

For these kids too there should be nice homes similar to old age homes, so that if the parents want to leave them there sometimes they can do. There they should have a special educator for them or music teacher etc. and it should also have good facilities such as cooler, fridge, TV etc. (Gita, Delhi parent)

The government should create such a home where the kids should not feel that they are in an orphanage but in my home. (Reshma, Delhi parent)

Providing appropriate financial help to their children was the second suggestion given by a number of Delhi parents:

Increase the pension because if the parents die, in ₹1500 for how many days these kids will be able to feed themselves. (Radhika, Delhi parent)

The third top suggestion given by the Delhi parents was that the government should provide vocational and/or employment related support to their children.
Some of these kids are quite different – for them there should be some kind of job system – some can go ahead in music or sport, some may have other activities – the government should think about them. (Hema, Delhi parent)

The other suggestions provided by both groups of parents included:

- open more leisure and recreation centres;
- provide meaningful activities for the adults with HCN;
- improve access in the community and raise public awareness;
- provide more choice and control to families;
- have flexible and streamlined support services (not segregated);
- provide a one-stop shop for all administrative services;
- invest in family-governed living models;
- provide better information to parents regarding their entitlements;
- provide health care close to home;
- provide better monitoring of disability service providers;
- just do something for these kids.

Key informants’ views

All the key informants were also asked to provide three suggestions for the policy makers and funders. The suggestions provided by both groups of key informants were very similar to those provided by the parents. Some additional suggestions that came from the key informants include:

- adopt investment approach to welfare;
- services need to be more outcome focused;
- have a better understanding of the ground reality – know the population better;
- provide for more disability qualifications at tertiary level;
- provide taxation benefits to attract more private funding;
- ensure that the laws promote supported decision making and not substitute decision making.

Suggestions for other parents

Table 4 summarises the parents’ responses around the three most important suggestions they had for other parents of adults with HCN.
Table 4.

*Three Most Important Suggestions for the other Parents*

<table>
<thead>
<tr>
<th>Suggestions for the other parents</th>
<th>Auckland Parents – Top Three Responses (n=14)</th>
<th>Delhi Parents – Top Three Responses (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Speak up for your child’s rights</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>2 Network with other families</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3 Look after yourself</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>1 Accept your child’s disability and love them</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>2 Take your child to some centre – don’t keep them at home</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>3 Train your child to be independent</td>
<td>5</td>
<td></td>
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</tbody>
</table>

The top three suggestions from the Auckland parents for other parents of children with HCN were that they should speak up and fight for their children’s rights, keep networking with the other families in a similar situation as theirs, and look after their own health and well-being so that they could continue to support their children.

The suggestions that I would like to give to the parents of other severely disabled people would be to keep fighting for the rights of your loved ones. Do not give up because we have only got as far as we are today because we have been a very squeaky wheel and I won’t let things go. (Holly, Auckland parent)

Reach out and know similar people in similar situations so that we can hold hands with one another. (Mrs D’souza, Auckland parent)

Have breaks so you have rest – you are not a machine and no one expects you to be a machine. (Wendy, Auckland parent)

On the other hand, the top three suggestions from the Delhi parents for the other parents of children with HCN included: accepting their children’s disability and loving them for who they were; not keeping their children at home all the time so that they don’t feel isolated and also learn some skills; and training their children to be as independent as possible in managing their own care and other affairs:
First, the biggest thing is we have to accept the truth – which is we have such a child and the second truth is that we have to take extra care of these kids than other kids. (Sunita, Delhi parent)

If possible take your child to any institution – don’t keep them at home. Keep them involved as much as you can. Try that they go somewhere. If you go to any function etc., don’t treat these children different from others – wherever you go, take them with you. (Radha, Delhi parent)

Try and teach your children as much as you can, don’t rely upon others, teach them to speak, eat, ask for help, so that they can express themselves if they need help. Don’t keep thinking that my child can’t do anything. Keep trying so that they become independent. If you teach them they can stand on their own feet and don’t have to depend upon others. (Reshma, Delhi parent)

The other suggestions for the parents given by both groups of parents included:

- Learn the system and know your entitlements
- Seek professional support – do not try to do it all by yourself
- Create a circle of loving people around your child
- Plan in advance for your child’s future
- Secure your child’s financial future
- Believe in your child’s abilities
- Appoint a welfare guardian or set up a trust

Some parents refused to provide any suggestions for the other parents as they were of the view that people need to find their own path as what works for one family might not necessarily work for the other.

I don’t think I can give them any suggestions. You find your own path. And my way, probably others wouldn’t want a bar of it. (Katie, Auckland parent)

I don’t think I am qualified to give any suggestions to parents. (Manju, Delhi parent)

**Key informants’ views**

The key informants were also asked to provide three suggestions for the parents looking after adult children with HCN. A couple of key informants mentioned that it was not
their place to provide any suggestions to the parents as the parents knew their own situation best and hence they did not answer this question. The suggestions given by the other key informants were no different to those given by the parent participants and their primary message to the parents was not to lose hope and keep fighting for their children’s rights.

People in child’s life
The parents were asked to name three people who, in their view, were the most important people in their child’s life besides them. It was specified to the parents that this question was not about the people whom they felt were playing an important role in the child’s life but the people that their children would name (if they were asked this question) as being important in their life. In other words, this referred to the three people with whom their children had an emotional connection or whose company their children enjoyed. The people named by the parents included other family members such as the child’s siblings, uncles and aunties, or grandparents; or friends and relatives; or their child’s support workers.

Table 5.

<table>
<thead>
<tr>
<th>Three Most important People in Child's life Besides Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>People in child’s life besides parents</strong></td>
</tr>
<tr>
<td><strong>Auckland Parents</strong></td>
</tr>
<tr>
<td>1 Family members only</td>
</tr>
<tr>
<td>2 Combination of family, friends and support workers</td>
</tr>
<tr>
<td>3 Support workers only</td>
</tr>
<tr>
<td>4 No other person</td>
</tr>
<tr>
<td><strong>Delhi Parents</strong></td>
</tr>
<tr>
<td>1 Family members only</td>
</tr>
<tr>
<td>2 Combination of family members and support workers</td>
</tr>
</tbody>
</table>

As can be seen in Table 5, for six Auckland parents, all three people that they identified as important in their child’s life included other family members. For six other parents, those three people included a combination of other family members, friends and support workers. One parent mentioned that the three most important people in her child’s life
were all the existing support workers; and one other parent suggested that there was no one else in her child’s life besides herself.

On the other hand, 16 Delhi parents identified other family members as the three most important people in their children’s lives. For only two parents, the three most important people included a combination of other family members and current support persons. Both these parents were from a higher socio-economic background and the current support person they referred to was the full-time maid they had hired out of their own financial resources to look after their child.

6.3.8 Final comments
At the end of each interview, the parents were invited to talk about anything else that they wanted to say or share, or to ask any questions they had of me. A majority of the parents had nothing more to add to what they had already shared during the interview. However, a few parents made some general comments around future uncertainty and confessed that this is a topic that affects all parents of children with HCN but for some reason many of them avoid talking about it or taking any concrete action.

I would just like someone to come here and wave a magic wand and sort things out for us. [big pause] I don’t know what would happen. We don’t know what the future holds and we need to make some decisions. (Donna, Auckland parent)

Till the time the parents are alive there are no worries – but the parents keep suffering. The parents suffer because they are thinking that what will happen to my child in the future. All parents have these worries whether rich or poor. (Mrs Sharma, Delhi parent)

Thinking about their children’s future welfare, it’s a fear that all parents will have. It’s deeply embedded and I think every parent would be worrying about that whether they communicate that or not…. But at least being able to communicate that and begin approaching the issue of the future – all parents will have to do that. (Lesley, Auckland parent)

A couple of parents also commented that taking part in the study helped them reflect and think about their children’s future.

See it also helps us actually go to the issue. See it’s the third person who is bringing it up. See we could have it [such discussion] amongst us but then who
do we talk to. I also mailed this [PIS] to our children, so you see how you have helped me. (Mrs D’souza, Auckland parent)

One Delhi parent who herself works as a special educator talked about how having a disabled child changed her life for the better:

I think that after Paras my life has changed a lot otherwise I would have been doing the same like being a teacher in a normal school. But now I am able to serve more people and more parents and when I comfort them or counsel them I feel so happy. When I am able to help other children, I feel so blessed that because of my son I am working in this field and I am making whatever little contribution that I can. So I feel happy and blessed. (Monica, Delhi parent)

6.4 Concluding remarks

As evident from the various participant quotes throughout this chapter, after having raised their child with HCN with such love and care all their life, facing the prospect of leaving that child under someone else’s care is something that not many parents find themselves prepared for. This chapter presented detailed accounts of the parents’ wishes and worries concerning their children’s long-term future; their views on the significance of both formal and informal support in the lives of their children after them, including some of the issues they face or foresee in accessing those supports; their views and experiences in relation to the attitude of the society and the state towards their children; and the changes they want to see happen during their lifetime so that they feel a little more assured about their children’s future when they are no longer there to advocate for them. The views of the key informants of both countries on formal and informal support and the public attitude by and large aligned with those of the parents. Furthermore, they also provided some added insight into some of the issues raised and the changes proposed by the parents.

The focus of the next chapter is on summarising the key findings listed in this chapter and positioning the same in relation to the relevant global literature and other international studies. Using the discussion in Chapter 3 around triangulation of rights, choice and support as the conceptual framework, the next chapter explores the impact of differences in the available support structures on the rights of adults with HCN; and discusses relevant implications for policy, practice and research at global level including specific implications for India and New Zealand.
Chapter 7. Discussion and conclusion

In order to give priority to the parents’ voice, it was decided to refrain from presenting in the previous chapter any evaluative analysis of the information they shared with me. It is now time to present a detailed discussion and interpretation of the findings with a view to drawing some useful conclusions. There are important points worth noting about my approach to drafting this chapter. First, I have been conscious of the position of empathic neutrality that I have adopted in this study as a researcher and therefore have tried to be as neutral and non-judgemental as possible in my interpretation and analysis of the material to minimise the effect of my personal values, assumptions and biases. Relevant international literature and/or findings of other research studies have been used throughout to support the discussion. Secondly, the primary focus of the discussion has been on the support needs of the adults with high and complex needs as against the disability population in general. Finally, as mentioned in the Methodology chapter, the triangulation of rights, choice and supports (Chapter 3) provides a theoretical and conceptual framework to guide the discussion in this chapter with the UNCRPD (to which both India and New Zealand are signatories) as the backdrop or the key guiding document. Therefore, a number of references have been made throughout this chapter to various articles of the UNCRPD and to the previous discussion under the triangulation chapter.

At this stage, it is important not to lose sight of my research aim and the primary research questions that I set out to answer through this study. Two broad research questions that the study sought to answer were:

- What are the wishes and the worries of the parents of adults with HCN concerning long-term care and wellbeing of their children?
- What type of supports (both formal and informal) do parents consider as being crucial for their children’s future, especially when they are no longer there to care and advocate for them?

The first two sections of the Findings chapter have provided a detailed account of the parents’ wishes and worries concerning their children’s long-term future in various support areas. Similarly, the sections on informal support and formal support have provided useful insight into the second research question around the support mechanisms that the parents consider and value as being useful for their children’s
future. In addition, the parents also identified a number of issues with both forms of support and provided some suggestions on how to improve the existing supports to better meet the future needs of their children. This chapter summarises the key findings of these four sections and uses the information shared by the parents in the other sections of the Findings chapter with a view to fulfilling the research aim of the study, which is: to make useful recommendations for design and delivery of disability services that cater to the specific support needs of adults with HCN and their families.

The first research question relates to the kind of future that the parents desire for their children; the second research question relates to the types of support that the parents value; and the research aim of being able to make some useful recommendations concerns the changes desired by the parents. Therefore, the discussion in this chapter is presented under the three broad sections entitled “Desired future”, “Desired supports” and “Desired changes.”

7.1 Desired future

The purpose of this section is to paint a picture of the type of future that the parents have envisioned for their adult children with HCN beyond their own lifespan. The desired future includes both the things that the parents want for their children so that they can live a good life – i.e., their wishes; and the things that they do not want to be part of that future as they might prevent their children from having a good life – i.e., their worries. There were some subtle similarities and some stark differences in the wishes and worries expressed by both groups of parents. This section begins with a summary of the key common themes that emerged from the information shared by the parents concerning their wishes and worries. The details of the differences within those common themes are then discussed under the sub-section entitled Influence of available supports on desired future.

7.1.1 Wishes

The Findings chapter provides a detailed account of the wishes of both groups of parents for their children’s future under each support area. The key themes that emerged from the findings are summarised below.

*Live at a place of their choosing*

In terms of long-term future accommodation for their children, the parents talked about different options including continuing to live in their family home, living in their own
home, moving to a residential home or living in a flatting situation with two to three other people. The parents wished that their children should be well supported to live in the accommodation option of their choice. Many Auckland parents also suggested that, if their children were to move into a flatting situation or residential home, they should either be able to choose where they live and who they live with or they should be placed with other people with similar (dis)abilities and interests.

**Receive good quality care**
The parents wished that, irrespective of the accommodation option chosen by their children, they should receive good quality care either by formally trained staff with disability-specific knowledge or by other family members or informal carers who know the child well. Some affluent Delhi parents also talked about appointing family-paid support workers (maids). To ensure that their children received good quality care, many parents also expressed a desire that someone else from their informal network, preferably a family member, should continue to provide oversight of the care provided by support staff.

**Maintain good mental and physical health**
Both groups of parents wished that their children should continue to maintain good mental and physical health. In this regard, they wished that the people around them had a good understanding of their children’s health related needs including their medical conditions; that their children received adequate medical care, aids and equipment to maintain good physical health; and that their emotional and spiritual needs were met adequately by people supporting them.

**Lead an active social and/or vocational life in the community**
Both groups of parents wished that their children should continue to lead an active social and/or vocational life. The activity options that the parents wished for their children to be engaged in included attending a day programme designed specifically for disabled people; attending community based activities of their choice; getting opportunities for pursuing their hobbies; getting a job; or being self-employed. A couple of Auckland parents also expressed a desire for their children to go on a holiday every now and again. Thus, overall, the parents wanted their children to live a happy and stimulating life, doing what they like.
**Have adequate funds to meet their individual needs**
The parents of both groups wished that their children should have sufficient funds to meet all their support needs including personal care needs, health-related needs and additional disability-related costs. With regard to the source of funds, the wishes of the parents within and across both groups differed and included full financial support from the government, supported through their personal savings or a combination of their personal savings and government support. Many Auckland parents expressed a strong desire that their children should have sufficient funds not only to meet their basic care needs but also for being able to do activities of their choice in the community.

**Be well supported in decision making**
Parents of both groups wished that their children should be well supported in the future with decision making and the management of their financial affairs. They expressed a desire for their children to be supported in this area by someone who understood their children well and who had consideration for their children’s best interests. The potential support options that the parents talked about included their other non-disabled children or other family members; legally appointed welfare guardians; or the members of a trust that they would set up in their child’s name.

**Be independent and self-reliant**
Many Delhi parents expressed a desire for their children to be independent in self-care and also be financially self-reliant either through a job or some form of self-employment so that they would not need to rely on anyone else.

In many ways, the wishes of the participants of my study for their children’s long-term future are neither uncommon nor unreasonable. The findings of some other, international, studies have been similar with regard to the parents’ or full time carers’ wishes for adults with intellectual and/or developmental disabilities. For example, the participants of a UK-based study examining the support needs of the ageing family carers of people with an intellectual disability also expressed a mixed preference for future accommodation ranging from a wish for their young persons to remain in the family home supported either by the family and/or paid staff, or moving to a residential facility with other people with similar disabilities (Taggart et al., 2012). In an Australian study examining the housing and support needs of adults with an intellectual disability, the participants reported a preference for living in community homes close to their peers.
for better social networking and demanded more choices in leisure and recreation activities (Shaw et al., 2011).

Similarly, a majority of the wishes expressed by my study participants are not unreasonable as they fall very much within their children’s rights as affirmed by various articles of the UNCRPD. For example, Article 12 talks about the right to support in decision making to exercise their legal capacity; Article 19 talks about the right to living independently and being included in the community; and Article 30 talks about the right to participate in cultural life and leisure and recreation (UN General Assembly, 2006).

There is one other wish expressed by many parents of both groups that has not been discussed thus far and that is a wish that their children should die before them. It raises a question as to why the parents living in the countries committed to protecting their children’s right to live a happy and healthy life would need to wish such a thing for their own children. The sections to follow provide a detailed insight into this predicament of the parents; however, a short answer to the question is the inadequacy of the existing support mechanisms to provide the necessary assurance to these parents concerning their children’s long-term wellbeing.

Having discussed the parents’ wishes, it is now time to discuss their worries concerning their children’s future after the parents pass away. Their worries are directly related to the issues they identified with their existing supports and hence are discussed in detail in the next section on desired supports. The next sub-section, however, provides a brief summary of the key worries that the parents expressed concerning their children’s future beyond their own lifespan.

### 7.1.2 Worries

The key themes that emerged from the worries expressed by the parents concerning their children’s future mirrored the themes discussed above regarding their wishes for their children’s future. In other words, a majority of their worries were related to a concern that their children might not get what they had wished for their future.

*Lack of choice and control*

One of the overarching worries of the parents across all the support areas was that, since their children were non-verbal, if people around them did not take the necessary time and efforts to understand their needs, wills and preferences the children would have no choice and control over what happened in their lives. They might not be able to choose
where they lived and who they lived with; who supported them; or what they did during the day. In the context of this study, the concept of *choice and control* is crucial and is raised time and again throughout this chapter.

**Poor quality care**
The parents of both groups were also concerned that the quality of care provided by the formal support staff or other informal carers might not be as good as they provide themselves. The parents felt that they knew their children the best, had years of experience of looking after them, and took meticulous care of their children’s every support need. They were, therefore, concerned that others might not be that knowledgeable, skilled or detailed in providing care and as a result their children might be subjected to poor quality care.

**Safety and security**
The parents also expressed a concern around the impact of lack of choice and poor quality care on general safety and security of their children. For example, the parents were concerned that if their children were forced to live with other residents who had aggressive behaviour that this could lead to safety issues. Similarly, the parents also felt that given the high support needs of their children, a lack of appropriate care and supervision could cause accidents. Some Delhi parents were even concerned that if an appropriate future living option was not sorted while they were still alive, their children might not have a suitable place to live, creating issues around their basic survival and safety.

**Deteriorating physical health**
One of the primary concerns for both groups of parents was that their children’s overall health would deteriorate once they were not there because even the health professionals struggled to understand their children’s conditions and associated health-related needs. The parents talked about them having to do a lot of interpreting for their children and explaining their medical conditions during medical appointments. They were, therefore, concerned that if people did not understand or misunderstood the non-verbal signs and gestures that their children use to communicate when they are unwell, this could result in their health needs being ignored or not met adequately.
**Lead a lonely, isolated and non-stimulating life**

In addition to the concerns around their children’s physical health, the parents were also worried about their mental health with their children potentially living a lonely, isolated and non-stimulating life being the most pressing concern. Many parents of both groups felt that, whilst they wanted their children to lead an active social and/or vocational life, they struggled to find suitable day programmes or vocational centres that could cater to the specific needs of their children. Further, the community-based activities were either not accessible or they could not afford the transport costs or the fees to attend such activities. As a result, they were worried that their children might end up either staying at home all the time leading a non-stimulating life or they might be forced to engage in unwanted or undesirable activities not of their choosing.

**Uncertainty and anxiety about future**

Many parents also expressed some general anxiety around what the future held for their children. These concerns ranged from uncertainties around the source of financial support to meet their children’s future support needs to who would take over all the multiple roles they performed as parents to whether the future decisions taken by others on behalf of their children would be in their best interests.

**Abuse**

Another major concern for almost all the parents was that their children’s reliance on others for all aspects of their support right from intimate level of personal care to financial management made their children very vulnerable to potential physical, sexual or financial abuse. The parents felt that the limited cognitive ability of their children to understand or interpret people’s actions not only made them an easy target for potential abuse but they might also not be able to report abuse if it happened and that their evidence might not be considered credible even if they did manage to report it somehow.

**Non-verbal communication**

Finally, a majority of the parents reported that their children were either completely non-verbal or had limited ability to communicate verbally in a clear manner. They often used non-verbal communication methods to express their needs, preferences and even feelings. Whilst their children being non-verbal was not a worry in itself, it was people’s limited understanding of non-verbal communication that was a major worry and it also formed the basis of most of the worries discussed above. Having lived with the child for
years, the parents understood what every facial expression, hand gesture, shake of the head or a grunting sound meant. However, they were concerned that those who did not know the child well would either struggle to understand what the child was trying to convey or, worse still, they might misinterpret what their actions and sounds meant. As explained by Williams (1991):

> Individual preferences of persons with disabilities are often ignored because their expressions have been seen by others as “aberrant,” “off-task,” “non-compliant,” “inappropriate,” “excessive,” “challenging,” “aggressive,” “self-injurious,” or “nonsensical,” and are rarely seen as attempts to communicate to others their valid wants, needs, fears, wishes, or desires. (Williams, 1991, p. 543)

Similarly, in a video resource created by the Complex Care Group on non-verbal communication, the parent participants reported that non-verbal people are often misunderstood as being “stubborn” or “aggressive” when they throw their arms in the air whilst walking (Complex Care Group, 2015).

Earlier we have discussed the parents’ worries concerning the impact on their children’s mental and physical health of the health professionals’ inability to understand non-verbal communication. Their care in other areas might also be similarly affected – for example, they might not receive good personal care if the support staff struggle to understand their needs; or they might not be able to live an enjoyable social life if people do not take time to understand their likes and dislikes; or inappropriate major life decisions could be taken on their behalf if their guardians or trustees struggle to work out what is in their best interests. Finally, the parents’ worry concerning their children getting manipulated or abused was also amplified by the fear that their children might not be able to report abuse or people might not understand their side of the story even if they reported abuse. Thus, the concern that people would not be able to understand their children’s communication was a key source of the parents’ worries concerning their children’s overall future beyond their own lifespan.

Similarly to their wishes, the worries expressed by the participants of the study have also been reported by the participants of some other studies, including being discussed in the international literature. For example, it is well recognised that loneliness and isolation are major issues faced by many young people with impairments (Shakespeare, 2014; Statistics New Zealand, 2014). In a New Zealand based project based on real life stories
of people with HCN, Milner and Mirfin-Veitch (2012) also found that the people living in their own homes faced a greater risk of isolation. Similarly, the concerns shared by my study participants around poor quality of care in formal services have also been reported by many other authors and researchers (Bray et al., 2005; Read, 2000; Taggart et al., 2012). In the words of Read (2000), “few disabled children are offered high quality services that are an acceptable alternative to the direct care and assistance provided by mothers” (p. 113). Finally, Scourfield (2005) and Milner and Mirfin-Veitch (2012) have also talked about the risk of abuse, particularly in home-based care where the support workers work in isolation without adequate monitoring or supervision.

Further, just as the key wishes of the parents for their children’s future are affirmed as their rights under the various articles of the UNCRPD, the Convention also provides for specific protection against some of the worries expressed by the parents. For example, Article 16 of the UNCRPD requires the state parties to take appropriate measures to protect disabled people’s right to freedom from exploitation, violence and abuse; Article 25 talks about the standard of health care; and Article 28 talks about an adequate standard of living and social protection (UN General Assembly, 2006). Further, within the New Zealand context, under the Code of Health and Disability Services Consumers’ Rights, all disabled people have the right to freedom from discrimination, coercion, harassment, and exploitation; the right to appropriate standard of care; the right to effective communication; and the right to make informed choice and give informed consent amongst others (Health and Disability Commissioner, 2017).

So the fact that, despite having the protection of the UNCRPD and other similar mechanisms, the parents have so many worries concerning their children’s future and that some even expressed a wish to outlive their children suggests that the existing support mechanisms in both countries are falling short of fulfilling the rights of people with HCN. However, as detailed in Chapter 4, disabled people and their families living in New Zealand have access to a much wider range of publicly funded disability support services and other financial benefits as compared to those living in India. Further, the existing support system section of the Findings chapter also suggests that the Auckland parents had better access to, and were more reliant upon, formal support, whereas the Delhi parents were generally more reliant on informal support, particularly from other family members. Therefore, as discussed thus far, whilst there are common themes in the wishes and worries of the parents of both groups, within those broad themes there
are differences in the specific wishes and the worries which could be attributed to the differences in the availability of formal versus informal support to both groups of parents.

7.1.3 Influence of available supports on desired future

As mentioned in the introductory chapter, the primary purpose of choosing the participants from both India and New Zealand was to provide a unique insight into what influence living in countries with varied levels of formal and informal support has on the wishes and worries of the parents of children with HCN concerning their children’s long-term future. The discussion in this section should help to gain such insight. It needs to be clarified that this section discusses the influence of the existing support (or a lack of it) at the time of the interviews\(^6\) on the parents’ wishes and worries concerning their children’s future. The parents’ views on the potential role that both formal and informal support could play in their children’s future lives and the changes that would be needed in both types of supports for those roles to be effective are discussed in the later sections of this chapter.

Before we discuss the differences in their wishes and worries, it needs to be reiterated that, despite the differences in availability of supports, both groups of parents had a number of common wishes and worries. In terms of their wishes, both groups of parents wanted their children to be well looked after, maintain good mental and physical health, and lead an active and stimulating lives. Many parents from both groups also expressed a wish to outlive their children. Similarly, both groups of parents expressed some common concerns around their children potentially receiving poor quality personal care, their health care needs being misunderstood or ignored, and their being potentially subjected to physical, sexual or financial abuse. These similarities in the parents’ worries and the wish to outlive their children despite the differences in the level of support they receive suggests that both formal support (irrespective of how well established it might be) and informal support (irrespective of its accessibility) are falling short in providing adequate measures and assurances when it comes to certain areas. The reasons for these inadequacies are discussed later in the chapter under the sub-sections of issues and challenges with formal and informal support. Let us now discuss the

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\(^6\) Interviews with Auckland parents were conducted between May and July 2015 and those with Delhi parents were conducted between July and September 2015.
influence of the difference in availability of both forms of support on the differences in
the wishes and the worries expressed by the parents.

The impact of difference in availability of formal support became most evident through
some of the worries expressed by the parents within and across both groups. For
example, uncertainty about the future was particularly worrisome for the Delhi parents
from lower socio-economic backgrounds. They were unsure as to where their children
would live, who would provide their day-to-day care and where the funds would come
from to meet even the most basic needs of life once they were no longer there to fend for
them. Some were even worried that their children might end up in an institution with
appalling living conditions or be left on the streets to starve. None of the Auckland
parents, on the other hand, expressed such a worry that their children’s basic survival
might be at stake after they were no longer alive. Their anxiety for their children’s future
was around where the funds would come from to meet the shortfall between the
government funding and the actual funds needed to meet their children’s extra
disability-related costs and the costs related to community-based activities which they
met out of their personal resources. Thus, their primary concern was that, without the
additional government funding, their children’s overall quality of life might be
sacrificed after parents died.

Similarly, the impact of lack of informal support was evident from the worries expressed
by the Auckland parents in the area of mental health. Many Auckland parents,
particularly those who had no involvement of other family members in their children’s
lives, expressed a concern that their children’s emotional well-being might be sacrificed.
As Lesley explained:

You can have paid supports to provide those essential cares in terms of meals
and personal care but it’s more about sense of family and emotional wellbeing
that’s what the concern is because who does provide that? Other than family
probably. Ya, that’s the question that perplexes all parents because you can’t
really buy that – you can’t buy that – it’s not a commodity that you can buy – it
has to be freely given. (Lesley, Auckland parent)

As mentioned in the Findings chapter, 16 out of 18 Delhi parents reported that the three
most important people that their children felt emotionally connected to were other
family members. That could potentially be the reason that the Delhi parents were less
concerned about emotional wellbeing of their children as they had taken such support from the other family members for granted. Many Auckland parents, on the other hand, reported that the paid support workers had become important people in their children’s lives. However, as discussed later under the section on formal support, high staff turnover is one of the major issues in relation to the disability workforce resulting in support workers constantly moving in and out of people’s lives. Thus, a reliance on paid support workers for emotional support poses a problem as personal connections and friendships take much longer to build.

An analysis of the differences in the wishes of both the group of parents in various support areas also made evident the influence of the differences in their access to formal versus informal support. In relation to future living arrangements, the primary preferences of many Auckland parents were for their children to either live in their own individual home or in a flating situation with two to three other people. This could be because they have access to service models such as home-based care and supported independent living (SIL), and hence felt assured that their children would be supported by paid staff in their homes. On the other hand, in India there is no such concept of publicly funded, home-based support and, therefore, a wish for their children to live in their own home or continue living at the family home was expressed by only those Delhi parents who could either afford to pay for home-based caregivers (maids) from their own savings or those who had access to the informal support of other family members. The rest of the Delhi parents wished that their children should live in a residential home after the parents had passed away as they could not think of any other option. Those Auckland parents who preferred out-of-home placement (such a residential home or flating situation) wished for their children to have a say in where they lived and who they lived with. For many Delhi parents, however, the option of a residential home was more out of compulsion than a choice and hence they did not particularly seem to worry about who else might live there so long as their children had a place to stay and someone to look after their basic needs at that place when they themselves were no longer alive. Nonetheless, they expected it to be a “nice” place where their children received good quality care.

The impact of access to formal versus informal support was also evident in the parents’ wishes concerning who should provide the day-to-day care to their children after parents could no longer do this. A majority of the Auckland parents expected support workers
paid through the formal system to provide daily care, whereas, a majority of the Delhi parents expected the other members of the family, particularly their other, non-disabled, children, to take over the caring role. Further, some of the wishes of the Delhi parents from lower socio-economic backgrounds also indicated how helpless a lack of formal support made these parents feel. Many Delhi parents wished that their children should become completely independent in personal care or be self-reliant in terms of finances. Some of these parents even mentioned that this was improbable given the nature of their children’s impairment, however, they were hoping against hope for these wishes to come true just so that their children would not need to depend upon anyone else or live at the mercy of others when they themselves were no longer there. Hatton et al. (2004) also found that when the parents are not very optimistic about the future, they tend to have unrealistic dreams such as their severely disabled children becoming “normal”.

When filtered through the lenses of our discussion in the triangulation chapter, the difference in available formal support to both groups of parents raises another very interesting element. By and large, the wishes and the worries of the Auckland parents were not guided by their own individual financial situation, whereas, in the case of the Delhi parents, the family’s socio-economic background played a major role in what they wished for their children’s future. The Delhi parents who were financially affluent were willing to leave behind enough resources for their children’s future and hence were not so worried about the basic survival of their children and could also wish for things like their children continuing to live at the family home or lead a good social life. The Delhi parents from low-income groups too, were willing to do whatever they could for their children but were aware of their own financial limitations and hence their wishes and worries differed significantly from those of the more affluent families. On the other hand, no such differences were observed in the wishes and worries of the Auckland parents from different socio-economic backgrounds. Some financially well-off Auckland parents also expressed concerns over inadequate government funding for meeting all the future needs of their children. They did not consider it to be their role to make financial provisions for their children’s future life. This raises important questions around the link between the welfare state and the personal responsibility of the families, and is discussed in detail under the section on issues with informal support.

In conclusion, the core difference between the wishes and the worries of both groups of parents for their children’s future, particularly in relation to their material welfare, could
be summarised aptly as the difference between “surviving versus living” – an expression used by Louise, an Auckland mother. Given the lack of formal support, whilst a majority of the Delhi parents were preoccupied with thoughts of meeting their children’s basis survival needs after parents have died, the Auckland parents had taken the basic survival for granted and were worried that, without appropriate additional support, their children might just survive but not be able to “live” the life. In other words, the Auckland parents were worried that their children might not be able to enjoy an active social life doing things in the community like other citizens do or be denied opportunities to exercise any choice and control over how they live their life. It needs to be re-emphasised, however, that those Delhi parents who were in a financial position to take personal responsibility for the future wellbeing of their loved ones or those who had good informal support from their other family members could still wish for a good quality of life for their children despite a lack of formal support.

7.1.4 Desired future – concluding remarks
This section summarised the key findings of the study with regards to the parents’ wishes and worries concerning their children’s future. Whist there were a number of common wishes and worries that both groups of parents expressed, there were also some significant differences that were discussed in relation to the level of support the parents have access to (refer to Figure 2). Overall, the parents of both groups wished for a future where their children could live a happy, comfortable, safe, and stimulating life – albeit there were differences in the parents’ views within and across both groups on what such a life comprised.

For many parents of both groups, however, the concerns around their children being abused, or being left vulnerable to state care, or having to live at the mercy of others were so strong that one of their wishes was that their children should die before them. The anxiety around their children’s long-term future could have significant negative impact on the parents’ lives (Bray et al., 2005) and therefore it becomes necessary that timely steps are taken to prevent that anxiety from reaching a stage where parents feel like outliving their children. As previously mentioned in Chapter 2, Morgan (2009) reported that “some parents have actually taken tragic steps to ensure they survive their child” (p. 20). The forthcoming sections on desired supports and desired changes discuss some of the measures that the communities and the governments need to take to provide
Figure 2.

Summary of Findings: Desired Future
the parents of children with HCN the necessary assurance around their children’s long-term futures.

7.2 Desired supports
The previous section discussed the parents’ vision of their children’s future including the influence of their existing support system on that vision. This section discusses the support necessary to convert the parents’ vision of the desired future into a lived reality for their children and thus relates to the second research question around the type of support that the parents consider as being crucial for their children’s future, especially when they are no longer there to care and advocate for them. This section, therefore, summarises and discusses the findings presented in the previous chapter under the sections “Formal support” and “Informal support”. In addition, it also discusses the findings of the section entitled Public attitude as it has direct implications on the level of support that their children receive from both formal and informal sources.

7.2.1 Formal support
This section begins with a summary of the parents’ views on the role that formal support could play or would need to play for their wishes concerning their children’s future to come true. It then explores in detail the link between the parents’ worries as discussed in the previous section and the issues/challenges with formal support.

Significance of formal support
A majority of the parents from both groups felt that for their children to be able to live the kind of future that the parents have envisaged, they would need formal support in all aspects of their lives. However, the findings reveal that the differences in the level of publicly funded services available to disabled people and their families in India and New Zealand did not only influence their wishes and worries (as discussed earlier) but also their expectations of the role that the formal support system should, and could, play in various aspects of their children’s future.

To begin with the parents’ wish concerning their children being able to live at a place of their choosing, the Auckland parents felt that the formal system could provide group homes or home-based support to live independently. Some Auckland parents suggested that government help could also be significant in renting or buying a separate house for their children. The Delhi parents, on the other hand, suggested that the formal system should provide suitable residential homes for their children. As previously mentioned,
the concept of publicly funded, home-based care does not exist in India and a couple of Delhi parents even mentioned that given the size of the population, it would be difficult for the government to provide support staff in disabled people’s individual homes.

But even the government would not be able to provide one to one service. How will they find so many caretakers? So that’s why there needs to be a residential institution where such kids can live together. (Radha, Delhi parent)

For their children to maintain good mental and physical health, whilst the Delhi parents talked about the significance of formal support in getting free basic health care and medical insurance, the Auckland parents talked about getting professional behaviour management support and personalised mobility equipment.

To fulfil their desire for their children to lead an active social and/or vocational life, both groups of parents felt that the formal support could be particularly helpful in providing publicly funded day/vocational centres that offer a variety of leisure and/or vocational activities suitable for people with HCN. Some Delhi parents felt that, even if their children did not get any monetary compensation for working at vocational centres, it could still provide them some gainful employment and help them with their self-esteem.

It may be noted that the day/vocational centres run by disability service providers are often criticised on the grounds that they do not allow interaction with other, non-disabled, people and that they provide good life only from 9am to 5pm (New Zealand Disability Support Network, 2016). However, as argued in the next section, different people prefer different outcomes and accordingly, a “9 to 5” good life with other disabled people might just be fine for people with HCN who would otherwise be isolated in their own homes – particularly if they struggle to afford the transport costs and fees for community-based activities. Further, a couple of key informants suggested that, in addition to helping children develop social and vocational skills, the day centres could also provide crucial respite to the family carers during the day. The significance of day centres in providing respite to the carers of disabled people has been emphasised in the literature for a long time (Allen, 1999) and it has been highlighted by the National Trust of India as one of the key objectives of their day programme scheme, “Vikaas” (The National Trust, 2017d).

With regard to their children’s future financial security, whilst the Delhi parents expected that the government should provide pensions sufficient to meet the basic care
needs of their children, the Auckland parents had taken the basic financial support from
the government for granted and expected the government to provide additional funding
for things such as transport costs and fees for community-based activities, housing
modifications, and paying a decent wage for their home support staff. Some Delhi
parents suggested that the government assistance in the form of offering their children a
simple job that they could do or helping the family in setting up a small business in the
name of the child could also be helpful in their children gaining some financial
independence.

Overall, both groups of parents felt that having appropriate formal support in all areas
could not only allow their children to have a good life but could also help other family
members to enjoy being just “the family” without having to worry all the time about the
child’s care. For example, as pointed out by one Auckland parent, if there was a formal
carer available to accompany them at family social visits, it would allow both the
disabled person and the family carer to have a good time with other family members.
Further, a number of parents suggested that looking after an adult child with HCN took a
very heavy toll on their mental and physical health and as a result they were very
grateful for the contribution of formal support in making their job a bit easier.

The discussion in this section suggests that the parents were not only reasonable in what
they wished for their children’s future but were also very reasonable in their
expectations of the formal support system in fulfilling those wishes. The Delhi parents
appreciated the potential limitations of the government in supporting such a large
population of disabled people and hence their expectations of the formal support were
largely limited to meeting the basic shelter, personal care and health care needs of their
children. The existing New Zealand formal support system provides for the basic
survival needs of its disabled citizens and hence the Auckland parents’ expectations of
the formal support were more around their children’s right to live independently and
participate in the community on an equal basis with others. In either case, referring back
to our discussion in the triangulation chapter, people with HCN and their families living
in both countries have rights to receive adequate support and having a choice in
receiving that support. It then raises the question, however, as to why, despite India too
being a signatory to the Convention, the Delhi parents did not have higher expectations
of the formal support system. The forthcoming section on the issues with formal support
reveals that there are a number of different reasons ranging from a lack of awareness
amongst the families of their rights and entitlements to a lack of trust of the system. However, one of the primary reasons, as alluded to earlier, is the link between the welfare state and the personal responsibility and this is discussed later in this chapter.

As mentioned in the Findings chapter, whilst discussing the significance of formal support in the future lives of their children, the parents of both groups also highlighted a number of issues with the existing support system. An analysis of these issues suggest that, despite formal support being so significant for their children to live an ordinary life, their right to adequate support and choice in receiving that support is not adequately met in a number of areas. Whilst the solutions proposed by the parents for resolving those issues and making the formal support system more accustomed to the specific needs of people with HCN are discussed in the section entitled “Desired changes,” the next subsection summarises and discusses the key issues raised by the parents of both groups with their respective formal support systems.

**Issues and challenges with formal support**

Given the differences in the availability of formal support in both countries, the issues and challenges identified by both groups of parents were also significantly different from each other and hence are discussed here separately for each group using the key themes identified in the findings chapter.

**Issues identified by the Auckland parents**

The Auckland parents identified the following key issues and challenges with formal support:

*Disability workforce related issues*

According to the Auckland parents, a lack of necessary skills and knowledge amongst support workers to work with people with HCN, a shortage of staff, and a high turnover of staff were the key issues they faced in relation to the disability workforce. These issues were the primary source of their worries concerning poor quality care and safety and security. Further, shortage of staff and high turnover also resulted in them having to put in a lot of extra hours themselves and a lack of consistency of people working with their children, respectively.

The issues around inadequate training and high staff turnover in the disability workforce in general have been reported time and again in the New Zealand based literature and in government reports (Beatson, 2004; New Zealand Disability Support Network, 2016;
Social Services Committee, 2008). The issues around staff training and poor quality support with a specific focus on people with HCN were first reported by Bray et al. in a report entitled “Evaluation of the complex carers group project” (Bray et al., 2005). Almost a decade later, in a project aimed at reviewing the training capability of the workforce for competently supporting people with HCN, acknowledging the findings of Bray et al., Te Pou reported that “given their small population size, complex needs, and frequent physical isolation, the needs of these disabled people and their family/whānau are often overlooked in workforce development and planning” (Te Pou o Te Whakaaro Nui, 2013, p. 10). The review also suggested that, in addition to the generic skills required to support disabled people, supporting people with HCN requires some specialist skills particularly in the area of developmental needs, health care needs, and assessment (Te Pou o Te Whakaaro Nui, 2013). The report highlighted some gaps in the existing New Zealand qualifications to equip support workers with all the necessary skills and made some recommendations for enhancing the workforce capability for better supporting people with HCN.

The parents were, however, empathetic of the situation of the support workers and suggested that the primary responsibility for the lack of skills and knowledge and high turnover amongst the support workers lay with the government because their work was not valued by the authorities; they were offered very limited training opportunities; and were also grossly underpaid with no career path. Similar to the lack of training, the issues around low pay and limited career paths for the disability workforce have also been raised time and again in the New Zealand literature. Praising the commitment of the disability support workers, Beatson argued for an increase in their remuneration in the following words:

Where care is good – and it often is – it is through workers’ personal dedication to the wellbeing of their clients, not their level of remuneration. This is admirable, but we do not expect similar altruism of lawyers, accountants or share brokers. There is a symbiotic relationship between the disabled and those who support them: the situation of the former would improve if that of the latter were valued in real rather than symbolic terms. (Beatson, 2004, p. xx)

The parents suggested that the issue of lack of knowledge related to their children’s high support needs did not only apply to support workers but also to health professionals,
staff of the needs assessment and service coordination (NASC) agencies and policy makers. Lack of understanding on the part of the NASC staff and policy makers on how having high support needs affects the individual and the entire family results in their needs not being assessed appropriately in the first place which, in turn, results in inadequate or inappropriate service options offered to them and their children. Similarly, according to the parents, many health professionals working with disabled adults did not have as detailed knowledge of their children’s complex medical conditions as paediatricians working with the younger kids had and as a result they struggled to provide adequate support and treatment to their children with HCN.

*Lack of age- and impairment-appropriate options*

A number of parents were of the view that day programmes, short-term respite homes, and even long-term accommodation options offered to their children were often not suitable for their age or were not adequately equipped to cater to their high support needs. The participants of some other research studies have expressed similar concerns over their children being admitted to an aged care facility (Shaw et al., 2011) or having to live far away from their community due to limited housing options equipped to cater to their high support needs (Milner & Mirfin-Veitch, 2012). Shaw et al. (2011) also reported that lack of affordable accessible housing for disabled people is an issue of global concern and the situation is becoming increasingly dire in New Zealand with a recent surge in demand for subsidised social housing for a range of beneficiary groups (New Zealand Disability Support Network, 2016).

*Lack of choice and control*

Due to their limited cognitive ability and non-verbal communication, the concept of choice and control becomes very complicated and contentious when it comes to people with HCN and hence it needs a thorough exploration. There is universal recognition that all disabled people, irrespective of the severity of their impairment, have a right to exercise choice when it comes to the services and decisions that affect their lives (UN General Assembly, 2006). Non-verbal people’s right to choice and control is expressed eloquently in “Outcome 7 – Choice and control” of the NZDS 2016-2026 in the following words:

> As we get older we will make our own choices and decisions on things that affect how we live our lives, including where we live. Some of us may need
support some of the time or all of the time…. Those of us who need support to communicate or make decisions receive it in an appropriate way at the right time and those decisions are recognised and respected…. In the rare circumstances when decisions need to be made on our behalf, they are based on the best interpretation of our will and preferences, as opposed to just thinking about what is in our best interests. Needing support does not diminish our independence or our ability to have choice and control over our lives. We will make informed choices based on what is available, rather than settling for a less desirable option because that is all that is offered to us. (Office for Disability Issues, 2016, p. 36)

Yet, as highlighted in the parenting chapter (Chapter 2) and in the triangulation chapter (Chapter 3), a number of things get imposed upon people with HCN and their families at various stages of their lives right from the onset of disability until the person dies and they seldom get any real choice in what happens in their lives. To begin with, they do not choose to be a disabled person or a parent of a disabled person in the first place. As narrated by Louise:

> It’s one thing to have a child with severe disabilities born to you. I didn’t choose it. So all this martyrship and all this oh you are so great and everything. Actually, I didn’t choose it…. Yes, I have not dropped the ball but I didn’t choose to do it. (Louise, Auckland parent)

Then as the child grows, the inadequacy of the system to meet their unique support needs means that they get offered limited options in all aspects of their life right from education to healthcare and later on in residential care and social and vocational opportunities. A detailed analysis of the information shared by the parents as well as the key informants suggests that there are a number of factors that lead to the failure of the formal support system in offering choice and control to people with HCN. These are limited service options, structured routines and programmes, substitute decision making, and a one-size-fits-all approach.

**Limited service options**

As discussed under the previous heading, the adults with HCN have limited service options when it comes to homes or day programmes that could adequately meet their support needs. According to the parents, this results in their children often being forced to accept what is available and thus have limited choice and control over where they live.
or who they live with. Similar issues around lack of choice in residential care were also raised by the parents interviewed by Milner and Mirfin-Veitch (2012). Further, when it comes to what they do with their day, if they cannot afford the costs associated with community-based activities, often the only real options available for people with HCN are to either attend a day programme that might be grossly unsuited to their needs or stay at home all day and live an isolated life. Thus, having limited service options directly impinges upon their right to “living independently and being included in the community” as prescribed under Article 19 of the UNCRPD (UN General Assembly, 2006).

**Structured routines and programmes**

A couple of key informants highlighted that an emphasis on structures and routines in services also deprive people of choice and control. Group homes and day centres often run on an economies-of-scale basis and, as such, people do not get the individual attention that they need. It has been suggested that, despite deinstitutionalisation, the residential group homes in New Zealand have created mini institutions (New Zealand Disability Support Network, 2016; Social Services Committee, 2008) as the people living in those homes still have very limited say over how they live their lives. Larkin and Mitchell (2016) suggested that community homes follow a routine that suits the service provider. The homes are often closed during the day and all the residents are required to attend a day centre. Similarly, Milner and Mirfin-Veitch (2012) found that day programmes are also often very structured and provide little flexibility to accommodate individual preferences or spontaneity.

**Substitute decision making**

Earlier, we discussed that their children being non-verbal was a major source of many of the worries expressed by the parents of children with HCN. It is suggested that people who are non-verbal also often get deprived of choice and control in their everyday life and others keep taking decisions on their behalf (Complex Care Group, 2015). This is because, as mentioned in the triangulation chapter, people tend to misinterpret their inability to communicate as an inability to make a decision or a choice, or worse still they are considered incapable of even having a point of view or a preference. Just because some people cannot verbalise their preferences it does not mean that they do not have a preference. The importance of giving non-verbal people opportunities to express
themselves in a manner that works for them has been emphasised in the literature for a long time.

Every person, regardless of the severity of his or her disabilities, has the right and ability to communicate with others, express everyday preferences, and exercise at least some control over his or her daily life. Each individual, therefore, should be given the chance, training, technology, respect, and encouragement to do so. (Williams, 1991, p. 543)

However, the inability of the support workers and other professionals to understand non-verbal communication combined with an assumption that non-verbal people are unable to make their own decisions results in none-to-limited consultation with people with HCN to ascertain their views and preferences. Further, as highlighted in the triangulation chapter, similar to communication, their lack of independence in personal care also often gets misinterpreted as a lack of ability to make decisions about their own care. As a result, invariably these people are subjected to “substitute decision making” where decisions get taken for them by others instead of “supported decision making” according to which they should be appropriately supported to make their own decisions and “retain the final say in her or his life” (Jameson et al., 2015, p. 38). To summarise in the words of Swain, French and Cameron (2003), “disabled people frequently find that [in the name of care] others are taking responsibility for them, over-protecting them, controlling them, abusing them and thwarting their autonomy” (p. 145).

One-size-fits-all approach

Finally, it needs to be noted that various authors agree that the newer service models such as individualised funding or direct payments potentially offer overall, better choice and control to disabled people and their families (Shakespeare, 2014; Taggart et al., 2012). However, Larkin and Mitchell (2016) argued that, “despite the long-term strategic shift to personalisation, with its emphasis on choice and control for those who use public services, there has been relatively little policy consideration of family carers’ choice within personalisation” (p. 189). In other words, the policy makers tend to adopt a one-size-fits-all approach and often do not consult with individual disability groups or their families concerning their specific needs and preferences.

Earlier in this section we discussed that structured routine is one of the factors that could limit people’s choices. However, as argued in the triangulation chapter, some people...
might actually prefer routine and familiarity over getting overwhelmed with choices. “The different ends which different people value might include: control over one’s own life; convenience and lack of responsibility; safety and security; companionship and intimacy; routine and familiarity” (Shakespeare, 2006, pp. 150-151). Thus, different people value different outcomes more than others. To take another example, not all disabled people or their families might be able or willing to accept all the extra responsibilities that come with some of the newer funding and service models.

Now they sit and say we have given you so many choices and you sit there thinking actually I don’t want to be overwhelmed with choices. I want something that’s going to work. I can’t spend ten years experimenting with all these crazy choices and they are all flawed and they all cause anxiety in some way so if they could just work something out that actually helped mothers that would be a far better idea. It’s not always as wonderful as it sounds. There are lots of traps in that system. (Joanna, Auckland parent)

Thus, such models would work only where the parents are available, able and willing to get involved. In other words, all choices do not necessarily work for people and not all people want choice and control. I believe, it is counter-productive to enforce a model designed to offer more choice on people for whom it is not the model of their choice in the first place. Not offering a choice to someone who wants to exercise choice and enforcing choice on someone who prefers something else over choice both amount to lack of choice and control. Further, given the earlier discussion around the potential increased vulnerability of the service users to poor quality care or even abuse in their own homes, it raises serious concerns over the desirability of direct payments as a model of service delivery for people with HCN, especially when their parents are no longer there to provide the necessary monitoring of the personal assistants. Thus, despite how promising it may sound in terms of offering more choice and control, individualised funding or direct payments as a method of funding the needs of adults with HCN whose parents are no longer there should be used with great caution.

Another area where a tendency to apply one-size-fits-all approach is seen is residential care. Whilst recent initiatives such as SIL and CCL designed to support disabled people in living independently in their own homes might offer more choice and control over where people live and who they live with, such models may not necessarily suit some
people with HCN. As mentioned earlier, whilst a majority of Auckland parents did prefer that their children lived in their own home or the family home, some Auckland parents wished for their children to live in a residential home after the parents died. They either felt that their children required a high level of medical care that could be safely provided in a group home with nursing staff or that a group home would provide a more stimulating environment than living alone at home.

Similarly, other researchers too, found that although full-time, out-of-home placement was not a preferred options for the parents, they were often left with no other choice when they were either physically no longer able to care for their children (Milner & Mirfin-Veitch, 2012) or when they did not wish to burden their other, non-disabled, children with the provision or supervision of care of their disabled siblings (Taggart et al., 2012). The participants of an Australian study examining the housing-related support needs of adults with an intellectual disability even reported a preference for co-locating people with different disabilities in large community homes because they felt that it might provide people with severe disabilities with “greater opportunities for social support and interaction with the wider community of people with a disability” (Shaw et al., 2011, p. 898). Shakespeare (2014) also argued that, for many disabled people, a group home may be a better option than living an isolated life in a private home.

Having the right to live independently in the community is a good principle, but in practice often translates into being isolated in a private home in the middle of a neighbourhood where there are few opportunities for networking or friendship. For many disabled or elderly people, attending a day centre or living in a group home may be preferable to being bored all day or living alone. Many disabled people are in the community, but not part of the community. (Shakespeare, 2014, p. 197)

It is, however, not necessary that living in a group home (small or large) would always result in better networking and friendships that Shakespeare referred to or the social support and interaction that the participants of Shaw and colleagues’ study talked about. As found by Milner et al. (2012), people find it difficult to develop friendships with their flatmates if they do not have much in common. That is perhaps the reason why some Auckland participants of my study expressed a wish that if their children lived in a
flatting situation or in a group home, they should be located with other people with similar (dis)abilities and interests.

In summary, for those with good support from informal network of family and friends who could either provide direct care or good oversight of home-based formal care, staying in their own home or a family home could be a desirable option; whereas, for others with a right mix of flatmates, a residential home might provide a more stimulating environment to live and avoid issues associated with isolation and loneliness. There is no one, single, right model or best model of supporting people in the community.

Critics of mainstreaming suggest we have replaced one kind of ‘one-size-fits-all’ approach to disability by another. In the old days, everyone was squeezed into the institutional mould. Today, they must conform to the deinstitutionalised model. Neither approach is sufficiently flexible or sensitive to accommodate the diverse identities, needs and interests of all disabled people and their families. (Beatson, 2004, p. xxix-xxx)

To conclude this discussion on choice and control, the parents’ overall wish of their children living a stimulating life in the future doing activities of their choice cannot be fulfilled if they are offered limited service options, are forced to follow a particular routine, are not given a chance to make their own decisions, or are forced to accept service models that do not work for them and their family. One size does not necessarily fit all.

Inadequate and inflexible funding

As mentioned briefly in the parenting chapter, people with HCN have certain unique personal support needs that must be met adequately for them to be able to live a happy and stimulating life. It is necessary to elaborate a bit more on those unique support needs to better understand why Auckland parents felt that the funding was an issue.

The adults with HCN often require certain extra products and services in their day-to-day life that many of the other disabled people do not need. For example, they might need incontinence pads, extra medication or specialised medical equipment due to their complex medical condition, personalised mobility aids and equipment, augmentative communication device or other communication aids, mobility transport, house modifications, safety gear and equipment, 24x7 care and supervision, behaviour support
services and so on. Whilst other disabled people may need one or more of the above products and services depending upon their impairment, many people with HCN are often reliant on all of the above to live a safe and comfortable life. The need for all these extra products and services mean a need for extra financial resources to procure them. In a New Zealand based study on the cost of disability, the additional costs for people with HCN were reported to be significantly higher across all areas of needs (Wilkinson-Meyers, 2010).

According to many Auckland parents, one of the biggest issues with formal support was a lack of adequate funding to meet all those additional needs and a lack of flexibility in what the allocated funding could be used for. They mentioned that even the disability allowance (designed to cover disability-related costs) that their children received over and above their supported living allowance was insufficient to meet all the extra costs that their adult children with HCN had. Similar to the other issues discussed so far, the issue of inadequate funding in the sector has also been highlighted time and again in New Zealand literature and studies (Beatson, 2004; Bray et al., 2005; New Zealand Disability Support Network, 2016; Wilkinson-Meyers, 2010). Bray et al. (2005) reported that, due to the additional disability related costs, many families of children with HCN even face financial hardship.

In addition to the direct support needs, the other area that gets impacted the most by a lack of funding is community participation. Article 19 of the UNCRPD requires the State parties to “recognise the equal right of all persons with disabilities to live in the community with choices equal to others” (UN General Assembly, 2006, p. 13) and Outcome 3 of the NZDS 2016-2026 also proposes that disabled people should be able to “participate in community activities on an equal basis with others” (Office for Disability Issues, 2016, p. 28). To that end, the service models such as SIL and CCL are designed to help disabled people live in and be part of the community. However, some Auckland parents were of the view that just living in a house in the community in itself does not amount to community participation. The person should be actually be able to leave the house and do things in the community and that would happen only if appropriate funding is allocated for that to take place.
On one hand they are saying we want disabled people to have an ordinary life, on the other hand the way that they fund people will never allow them to live an ordinary life without unpaid support. (Louise, Auckland parent)

This whole idea of inclusion in the community doesn’t actually work unless you put the support there for the person…. I think it’s a pipe dream and unrealistic. (Judi, Auckland parent)

Shakespeare (2014) argued that financial constraint is one of the factors that prevents disabled people from accessing community which, in turn, results in them facing social isolation:

Community care has ensured that most people with impairments live in local neighbourhoods, not in segregated institutions, but many disabled people remain effective prisoners in their own homes. This may be because of environmental barriers, lack of money, feelings of vulnerability, or problems with mobility. (Shakespeare, 2014, p. 191)

As mentioned in the previous section, the expenses associated with the activity fees and transport costs make participation in community based activities unaffordable for many families. Further, many parents, including those receiving individualised funding, suggested that the restrictions placed on the use of funding prevented them from adapting it to suit the specific needs of their children. Other New Zealand based studies and literature also suggest that the funding levels for community participation in New Zealand are “woefully inadequate” (New Zealand Disability Support Network, 2016, p. 18); are a major obstacle to community participation alongside physical and attitudinal barriers (Wilkinson-Meyers et al., 2014); and they often force the families to rely upon their informal support network for additional funds (Milner & Mirfin-Veitch, 2012). So when the formal support falls short of meeting their needs, the family’s options are to either fund those needs from their personal resources or not access certain services and suffer the consequences.

Referring to the NZDS 2001, Beatson (2004) argued that despite the high aspirations set by the strategy, disabled people often only got what the services could afford rather than what they actually needed. “The Disability Strategy calls the tune, but does not say who is going to pay the piper” (Beatson, 2004, p. xix). After over a decade since Beatson’s comments, the participants of my study, as well as those interviewed by the New
Zealand Convention Coalition Monitoring Group (2015b), still raised similar issues around the economic considerations overriding their real support needs. Thus, it could be argued that since New Zealand’s ratification of the UNCRPD in 2008, the Convention has been calling the tune but the progress has been slow because the “progressive realisation” clause\(^7\) allows for the piper to be paid in small instalments.

**Little consideration of family situation**

When it comes to people with HCN, their needs cannot be seen in isolation from the entire family’s support needs, especially when they are living at home with their parents and/or other family members. As discussed earlier, people with HCN have lots of extra support needs including a need for 24x7 care and supervision. However, the funding provided by the government for home based support often covers a very small proportion of care hours and the parents are expected to put in a lot of extra hours to cover unfunded care. Further, the care required is often physically demanding and hence it has implications not only on the care providers’ time and financial resources but also on their health. This reliance on parents to put in extra hours continues as long as the child stays at home and, as a result, often the parents are forced to look for out-of-home care when they reach a point where they can cope no longer. The participants in other studies have also reported that their need for support with the demands of caring including respite care is often ignored until they reach a point of crisis (Bray et al., 2005; James, 2013). Thus, even where support is available to the parents to provide care, it is often inadequate and is provided without adequate consultation with the affected families.

Further, as discussed in Chapter 2, the formal support system expects the parents to play multiple roles in the lives of their adult children with HCN including being their support person, funds manager, or supervisors of formal care; and yet, as the literature suggests, they are provided little support in helping them carrying out these roles effectively (Bray et al., 2005; Larkin & Mitchell, 2016). Thus, these parents’ entire lives revolve around their child with HCN leaving them little time for themselves or for other family members. This in turn takes a toll on the parents’ health (Morgan, 2009) and has a potential for creating negative impacts on family well-being (McConkey, Gent, &

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\(^7\) Refer to the triangulation chapter (Chapter 3) for a detailed discussion of the "progressive realisation" clause.
Scowcroft, 2011) and/or interpersonal relationships (Laskar, Gupta, Kumar, Sharma, & Singh, 2010).

According to Singer, Biegel, and Ethridge (2012a), the negative impact on the health and the social life of the parents and other family carers are the hidden social and emotional costs of family caregiving that are often unrecognised. They suggested that “two major ways that family caregiving is similar regardless of the disability of the care receiver are the kinds of supports families need and the potential financial, social, and emotional costs of family caregiving” (Singer et al., 2012a, p. 18). I would, however, argue that the level of support needed and the corresponding impact on the potential social and emotional costs would still be much higher for the parents of children with HCN than those for other disabled people with less intense care needs.

Many Auckland parents were of the view that the government did not understand or appreciate the realities of their lives and had little consideration of their situation because their voice is seldom heard. People with HCN are not represented well in various disability forums as their parents do not have time or energy to attend such forums and those “able disabled” who claim to be their representatives have limited understanding of their needs. Rosemary explained the plight of her and the other families’ situation in the following words:

There is a real need for understanding of the realities that our families have…. I think we are severely marginalised by the able disabled in the disability sector. They have really strong views on – they don’t want us to speak out on behalf of our kids, it’s their role. I don’t presume to know how somebody who is deaf or blind or has got CP and how their life is and I don’t think they should presume to know what someone with severe autism and epilepsy’s life is. They mention nothing about us without us, [it] doesn’t seem to apply to our kids…. So we feel because they [children with HCN have] got no representation or voice that that’s why they don’t have policies and services written to meet their needs.

(Rosemary, Auckland parent)

Therefore, the government needs to ensure that they consult appropriately with different groups as not all disabled people can fairly represent other disability groups. A detailed discussion around appropriate ways of consulting with people with HCN and their parents is provided in the section on “Desired changes.”
**Fragmented, complex and inconsistent support systems**

Finally, many Auckland parents also suggested that the formal support systems in New Zealand were too complex to navigate, were fragmented in approach and provided inconsistent support particularly due to multi-agency involvement. The parents echoed the issues highlighted in both the New Zealand and the international literature. The specific issues raised include lack of access to relevant information about available services (Bennett, 2002; New Zealand Convention Coalition Monitoring Group, 2015a; Redmond & Richardson, 2003); having too many different funding agencies (Beatson, 2004; Wilkinson-Meyers, 2010); uncoordinated and bureaucratic services (James, 2013; Wills & Chenoweth, 2005); and disparity in funding provided by different agencies (New Zealand Convention Coalition Monitoring Group, 2015b; New Zealand Disability Support Network, 2016).

Lack of coordination amongst various agencies and a bureaucratic culture leads to a situation where disabled people and their families do not receive services that can adequately meet their “whole of life” and “all of life” support needs. As argued by Wills and Chenoweth (2005):

> We contend that managerialism has created a culture of compliance rather than a culture of support whereby agencies are driven by technical and bureaucratic requirements rather than what it takes to support disabled people and families to live ordinary lives in their communities. (Wills & Chenoweth, 2005, p. 50)

Thus, agencies often focus more on meeting the regulatory standards or other legal requirements as opposed to finding creative ways of supporting disabled people.

**Negative attitude of the state**

In the previous section we discussed that their children being non-verbal was one of the overarching factors responsible for many of the parents’ worries. Similarly, many Auckland parents were of the view that the negative attitude of the state towards disability and disabled people was the primary reason for many of the issues with formal support discussed thus far. In response to the question on their views on the government’s attitude, many Auckland parents felt that the government considered disabled people to be a cost to the economy; they did not care about what disabled people and their families had to say; they often adopted a “we are the professional experts” attitude and that there was a lack of understanding of disability on the part of
the officials making decisions. Many Auckland key informants also shared similar views with regard to the attitude of the government towards disabled people.

The international disability literature and research supports the views of my study participants around a lack of government recognition of the pressures on the parents of caring for a disabled child (Bennett, 2002); the attitude of considering disabled people as a cost burden (Chakravarti, 2008); the professionals’ attitude of their expert knowledge being more valid (Swain et al., 2003); a lack of consultation with the families around their needs (Bray et al., 2005; McCallin, Dickinson, Weston, AUT University, & Waitemata District Health Board, 2007); and a need for government recognition of the real cost of providing adequate services (New Zealand Disability Support Network, 2016).

Talking specifically about people with HCN, the parents felt that the state did not consider them as valued citizens and hence their needs were either ignored or not given due attention. Holly expressed her frustration over the attitude of the state towards their children in the following words:

> Our kids do not ask to be disabled and why our people are not valued as much as you value those who are in prison who have got there through their own stupidity. (Holly, Auckland parent)

A probable explanation for people with HCN being less valued comes from our discussion in the triangulation chapter around the neoliberal concept of a reciprocal relationship between rights and responsibilities. According to the neoliberal principle, for people to access social rights there is an expectation to contribute back to the society often through paid work (Oliver & Barnes, 2012). Many disabled people struggle to reciprocate in such a manner as discriminatory employment practices and environmental barriers often prevent them from taking paid work. However, as argued in the triangulation chapter, when it comes to people with HCN, they are unable to take certain responsibilities such as paid work even if they wanted to or were not discriminated against. Nonetheless, they still become the victims of such neoliberal thinking and as a result are not considered worthy of social rights. Further, as explained in the parenting chapter, participating in the community as a citizen also often implies political participation and communicative competence. People with HCN often lack in both and hence are not looked upon as valued citizens. As argued by Vorhaus (2014), “we owe it
to them to provide a conception of citizenship that does better justice to their lives than any whose primary dimension is participation in political decision-making” (p. 618).

It may be noted that a majority of the issues discussed so far have global implications with the formal support systems of both developed and developing countries. However, disabled people and their families living in developing countries such as India face some additional issues in relation to formal support. These are now discussed.

**Issues identified by the Delhi parents**

The Delhi parents highlighted the following key issues with formal support:

*Minimal or non-existent financial support*

As mentioned in the disability support services overview chapter, in India there is provision for disability pension or unemployment allowance for those unable to work as a result of disability. However, the parents reported that the pension was not available for all disabled people in all the regions of the country and the amount offered was hugely inadequate to meet even their basic needs, where it was available. In India, the disability pension schemes differ significantly from one state to another. Some of my study participants reported receiving ₹1,500 (just over NZ$30) per month in Delhi. However, some states offer no pension at all and some (for example, Gujarat) offer as little as ₹400 (just over NZ$8) per month (Department of Social Justice and Empowerment Gujarat, 2017) which adds insult to injury.

Acknowledging the limitations of the social protection systems in meeting the welfare needs of the intended beneficiaries, the 2009 World Bank report on the status of people with disabilities in India suggested that “safety nets for PWD offer low coverage and limited financial protection” (The World Bank, 2009, p. xviii).

*Bribery and corruption*

Many Delhi parents suggested that bribery and corruption had plagued the formal support system in India. As detailed in the Findings chapter, the associated issues included the full amount of funding not reaching the needy; the families and the NGOs often having to bribe the government officials to get their allocated funding/grant; and that there were a number of schemes and services available only on paper but were non-existent or poorly implemented on the ground. This is one of the reasons why some parents had very few hopes or expectations from the formal support as they did not trust
the system. In addition, according to some key informants, the process of funding the NGOs was also very bureaucratic and lacked accountability.

**Lack of suitable residential homes and day centres**

A number of parents suggested that there were not many private options when it came to residential homes and the state-run homes offered appalling living conditions and very poor quality of care. Many state-run residences still operate on an institutional model where its residents have absolutely no choice or control over what happens there. In a Flemish study, De Waele and Van Hove (2005) provided a detailed account of the life of the residents living in a residential institution and argued that such an environment has more adverse impact on the quality of life of people with HCN than other disabled people. Their study found a number of issues with residential care with the key ones being that only the basic personal care and safety needs of the residents were met, strict routines were followed resulting in residents having no choice and control, and there was strong power imbalance with the staff and the authorities exerting their superiority over the residents (De Waele & Van Hove, 2005).

> When the usual things that make life nice and worthwhile become ‘extra’, living becomes surviving. Everything that goes beyond this is seen as a surplus value to which these people are not entitled. If they get any of this, it is seen as a special gift. (De Waele & Van Hove, 2005, p. 630)

Talking about normal things is turned into ‘being allowed to’. Residents also ask very frequently if they can have permission to do things. It shows how dependent they are, not merely because of differences in capacities but because of differences in authority. (De Waele & Van Hove, 2005, p. 632)

All these matters make us wonder who lives here anyway? (De Waele & Van Hove, 2005, p. 633)

Based on my personal observation of a residential institution that I visited during my fieldwork in Delhi, I would suggest that lives of the residents in that facility was not much different from that described in the quote above. Due to such living conditions, many Delhi parents expressed reluctance to send their children to government-run residential homes. Highlighting a need for smaller group homes, Chakravarti (2008) pointed out that “long-term institutional care [residential homes], especially for severely disabled persons, has not been seriously considered in the Indian context” (p. 357) and
that “the Western model of the ‘modern’ institution, which can take over the caring functions performed by the family, has not been considered” (p. 357).

Many parents reported that, similar to residential homes, there were also limited options of suitable leisure and recreation programmes or vocational activities for people with HCN. Further, some parents suggested that the homes and day centres operated by the parent-run NGOs were better; however, there were very few such organisations and due to lack of government funding they charged a very high fee that many families, particularly those from lower socio-economic backgrounds, could not afford.

As mentioned in Chapter 4, the Indian government focuses more on prevention and early intervention services but attention must also be diverted towards expanding and improving other disability support services to improve the lives of disabled adults including those with HCN. Acknowledging the lack of suitable service options for people with HCN right from schooling to adult services, the Rehabilitation Council of India (2014) reported that there were very few organisations that offered services to people with multiple disabilities and that a vast majority were served by organisations that were not equipped to meet their needs. The report also highlighted a need for more comprehensive research on supporting people with multiple disabilities and to guide the development of professional services that span across their lifetimes.

**Inaccessible health care and administrative services**

In addition to the issue of lack of knowledgeable health professionals as highlighted by the Auckland parents, having to travel long distances and waiting in long queues to access free health care were other major issues faced by many Delhi parents. Free health care is often available in India in only certain government hospitals and hence is always under heavy demand from various beneficiary groups. Some parents talked about avoiding having to take their children to a hospital when they were unwell because they could not afford the transport cost or their children could not manage the day-long wait at the hospital. Those who could afford it preferred to pay and go to a private clinic closer to home rather than travelling long distances to a public hospital to access free healthcare. According to the World Bank report, the key barriers to accessing health care for people with disabilities in India included poor attitudes and lack of knowledge amongst health professionals; poor physical access to health facilities; a shortage of rehabilitation staff; a poor referral system; and financial constraints (The World Bank,
Chakravarti (2008) argued that inaccessible health care could have a negative impact on the quality of life of disabled people as well as their families.

Similar issues were also reported by the parents for accessing disability administrative services such as getting a disability certificate for their children or getting information on their entitlements. The parents reported having to travel long distances and/or making multiple visits to get the disability certificate due to bureaucratic processes. Further, there is no designated agency (similar to the Disability Information and Advisory Services in New Zealand) responsible for disseminating information to disabled people and their families on publicly funded services and, as a result, many families are ignorant about their entitlements. A majority of the parents in my study were unaware of the new National Trust schemes. Highlighting the issue with the disability certification process, the World Bank report suggested that “current disability identification and certification system functions poorly, with poor skills among providers, awareness among PWD low, and rural outreach poor” (The World Bank, 2009, p. xvi).

Lack of trained support workers
As mentioned in Chapter 4, there is a great emphasis in India on the training of special educators and other rehabilitation professionals, however, there is only one certificate course relevant to the training of disability support workers. Since there is no concept of government-funded, home-based support services and there are very limited residential homes providing 24x7 care to disabled people, there is no designated workforce of disability support workers. In residential homes, care plans and day programmes are often prepared by the special educators and personal cares are often provided by the aayas (maids) who have no disability-specific knowledge or training. A couple of Delhi parents reported that they struggled to find appropriate support people to provide home-based care to their children even if they were willing to pay.

The facilities that are available there [in New Zealand] for free, if such facilities are available here even on payment that will be great. We don’t find caregivers to come home even if we are willing to pay. There is no such organisation that provides caregivers for disabled people… If we find caregivers then we even won’t have to think about putting him in a home. (Mr Shah, Delhi parent)

In addition to residential homes, the parents also raised concerns over the quality of staff employed by day/vocational centres and suggested that the care needs of their children
in such centres were often blatantly neglected. The available literature suggests that, besides the shortage of staff and lack of training, other issues related to the disability workforce in India include care work being considered menial and degrading (Chakravarti, 2008); and poor compensation, professional burn-out, and brain drain to developed countries (Rehabilitation Council of India, 2014).

As discussed earlier, almost all Auckland parents felt that the government’s negative attitude was responsible for inadequate services for their children. Delhi parents, on the other hand, were largely divided in their views on government attitude. There were many who felt that the government’s attitude was negative and they provided only lip service, however, there were also many who felt that the government had a positive attitude and they tried to do whatever they could within their limited means. Moreover, as discussed in detail later, the Indian families generally tend to consider it to be their primary responsibility to look after their children and hence whatever little government does is considered a bonus.

**Formal support – concluding remarks**

In this section it was discussed that the participants of both countries felt that formal support was extremely significant for their children to live a good quality life. They were, however, concerned that if the existing issues with the formal system were not resolved, these would continue to impinge upon their children’s right to receive adequate support in the future when parents were no longer there to advocate for them. Given people’s lack of understanding of their children’s complex needs and the negative attitude of the state, the Auckland parents felt that their children would be very vulnerable if left under the state care. Katie asserted:

> In fact, to pass Evan on to the MoH care, I think it’s just a short cut to the cemetery. Because the first thing they would do is to stick tubes in his body and then they don’t have the people to care for him. And we have been to so many funerals – I could cry now. (Katie, Auckland parent)

On the other hand, many Delhi parents did not believe that the government could practically provide adequate services for all disabled children, and even if provision was made, they did not trust that the services would reach their children due to the formal system being very corrupt.
There is so much corruption around the entire system. Even if there is any government aid, it doesn’t reach these children…. The government has taken out a lot of shops for such kids – for example, petrol stations, oil shops etc. – but they just don’t get anything. In government, everything is on the paper but there is nothing in practice. (Ms Sethi, Delhi parent)

For the reasons above, despite the differences in the support that the Auckland parents and the Delhi parents got from their respective formal systems, many parents from both groups expressed a desire to outlive their children as they could not bear the thought of their children being left vulnerable to state care. Thus, to assure the parents of children with HCN regarding a better future for their children beyond parents’ lifetimes it would be crucial that the issues discussed in this section are given due consideration. The parents also suggested a number of changes that could be helpful in resolving these issues. However, before we discuss the changes proposed by the parents, it is now time to discuss the parents’ views on what role informal support could play in meeting the future needs of their children.

7.2.2 Informal support

In line with the discussion in the previous section on formal support, this section also discusses the parents’ views on informal support under two broad headings, namely, significance of informal support and issues and challenges with informal support.

Significance of informal support

The key themes that emerged during my conversation with the parents around the significance of informal support are now discussed.

Help lead a stimulating social life

Both groups of parents wanted their children to lead an active and stimulating social life but were worried that given the lack of appropriate day programmes and inaccessible or unaffordable community activities, they might end up leading unstimulating and isolated lives. However, they felt that the informal support of family, friends and other members of the community could be most helpful in helping their children engage in social and leisure activities either at home or in the community in the form of playing games or taking them out to a park or a beach, etc. They felt that people find it easier to provide such support as it could be done without any fixed commitment of time and resources. People could help according to their capacity and availability and, at the same time, it
would provide a variety of people and activities to the disabled person. Formal support cannot replace such spontaneous support given voluntarily by people from the informal network.

**Provide support across different areas**

As discussed earlier, the parents play multiple roles in the lives of their children with HCN including being their primary carer, their friend/companion, their interpreter, their advocate, their welfare guardian, and their financer or finance manager. A closer look at the findings suggest that, whilst it might be difficult for any one single person to take over all the roles from a parent, different people from the informal network could certainly play different roles at different times. The parents talked about the potential role of family and friends in providing emotional support and friendship; neighbours in being helpful in the situations of emergency; and close relatives or members of parent support groups in acting as legal guardians or trustees. Such support from the informal network could help avoid issues associated with isolation and loneliness, safety and security, and decision making. Some Delhi parents even talked about their other, non-disabled, children taking over the full-time caring role from them and close family and friends potentially providing either one-off or ongoing financial support.

Thus, a well-established informal network could provide parents with a larger pool of people to rely upon when they are not around. If extended family members, friends, neighbours, parent support groups, church groups or even other members of the community are all involved in a person’s life, they could all be helpful at different times under different circumstances creating a safety net around the person. A welfare guardian living in a different city might not know what happens on a daily basis in the house but a neighbour could certainly keep watch and possibly protect.

Similar findings on the significance of informal support have also been reported in the studies involving people with mental health issues. Leach (2015) reported that “social support” (informal support) could be particularly helpful in the areas of friendship, emotional support, finding meaning, offering advice, and providing material assistance. They too, emphasised a need for having a range of different people involved including self-help groups and community organisations in providing support in all of the above areas rather than just one or two people doing it all.
Provide oversight of formal support

Many parents were of the view that, in addition to providing direct support in the various respects described earlier, informal support could also be very helpful in providing oversight and monitoring of the quality of formal care. Having someone from the informal network providing oversight could help with the parents’ worries concerning quality of care and safety and security and could also potentially avoid abuse and neglect. In other words, the informal network could provide another layer of accountability. A couple of Auckland parents also felt that if they were not around, in addition to providing oversight, people from the informal network could also be helpful in advocating for their children’s rights and helping them access appropriate formal services.

Provide respite to full-time family carer

A few Auckland parents and many Delhi parents found informal support of family and friends to be very helpful in providing them with crucial occasional respite and felt that in future they could continue to provide such respite to other family members taking over the caring role from them. Participants in some other studies have also reported that the support of friends, relatives and the families of other disabled people could be crucial in this area as well as being a source of advice, moral support and inspiration (Bray et al., 2005; Lindblad, Holritz-rasmussen, & Sandman, 2007). It may, however, be noted that whilst informal support could certainly be useful for one-off or occasional respite, for the reasons explained in the section on issues with informal support, it could not and should not be relied upon as a regular form of respite. A full-time carer’s need for respite must be formally assessed and provided consistently for it to work effectively.

Provided out of genuine love and care

Finally, many parents as well as the key informants felt that, in certain areas, such as emotional support and friendship, informal support could be more significant than formal support as it is often provided by people acting out of genuine care, concern and love for the person as opposed to it just being a job. A family member or a friend who has a relationship of mutual trust and respect with the person is more likely to care about the person’s welfare than someone from a formal system. As explained by Bray et al. (2005), “informal carers both ‘care about’ and ‘care for’ the disabled person, in contrast
to formal carers who undertake the tasks of caring but are not expected to care about the person, to the extent that kin do” (p. 5).

Emphasising the crucial role of informal support in the lives of disabled people and their families, Lindblad et al. (2007) asserted that, “according to our interpretation, informal support means a life enriching togetherness, the core of which is natural human caring” (p. 238). They further argued that:

In contrast to professional support, which is planned a long time ahead, the informal support is experienced as mostly offered spontaneously and in accordance with the families’ current needs. This is perceived as an expression of caring coming from ‘the heart’ and told as especially appreciated. (Lindblad et al., 2007, p. 243)

In summary, a majority of the parents from both groups, including those who did not receive much informal support themselves, were of the view that informal support could potentially play a very significant role in the lives of their children after the parents died. However, they also highlighted a number of intrinsic and extrinsic factors that, in their view, would continue to pose challenges to their children having access to appropriate informal support when parents were no longer alive.

**Issues and challenges with informal support**

The parents highlighted the following key issues with and challenges in accessing informal support.

**Intimate and complex nature of care**

As detailed in the Findings chapter, the parents of both groups felt that when it came to personal care or health related needs, the level of care required by their children was too intimate and/or complex to expect people from the informal network to provide it. Further, as the child grows older, the care becomes physically more demanding and complex to manage and this further reduces the chances of getting informal support for adults with HCN. A reluctance on the part of the parents to rely upon informal support for the personal care of their children with severe disabilities has also been reported in other studies (Hatton et al., 2004). A couple of key informants, however, cautioned that, even if informal support was available in the area of personal care, the parents should not rely on it too much as it might not be of a satisfactory standard because the informal
carers often do not possess the necessary skills and training to provide such sensitive and complex care.

Earlier it was discussed that informal support could be significant in providing social support and in providing occasional respite. However, a couple of parents suggested that their children’s care needs being too intimate and complex also reduces the amount of support they receive even in these areas as the person providing the support might be required to provide personal care during those social interactions. Thus, occasional informal respite that otherwise could be available to the carers of other disabled people in the form of their children going for outings with relatives or for a sleepover to their friend’s place is also seldom available to these families.

**Siblings have their own lives**

A number of studies have reported siblings to be a valuable source of support in the lives of people with an intellectual disability or high support needs (Hewitt et al., 2013; Lindblad et al., 2007; Zendell, 2010). Some Auckland parents were, however, of the view that siblings should be allowed to live their own lives without the burden of having to look after their disabled brother or sister. The parent participants of the study conducted by Lindblad et al. (2007) also reported similar uncertainty over the role of the siblings as they did not want to burden their non-disabled children with the caring role. Zendell (2010), on the other hand, reported that as the parents age, more and more families rely upon adult siblings to take over the caring role or meeting the social needs of people with an intellectual disability in later life. Unfortunately, however, the support needs of siblings themselves are often not adequately met by the service system (Zendell, 2010) and have received little attention from researchers (Hewitt et al., 2013).

The concerns reported by the Delhi parents in this regard were of a different nature as they expected their non-disabled children to play an active role in the future care of their disabled siblings; however, they were concerned that their children might not get the necessary support from their life partners or in-laws once they were married. This raises an important question around the impact of social structures on the availability of informal support of other family members. In the family oriented social structures of India, siblings are expected to (and are often willing to) play a supportive role in caring after their disabled brothers or sisters (Pinto & Sahur, 2001). Similarly, it is reported that in New Zealand, informal support is more readily available to Māori and Pacific Island
families as they tend to share child-rearing responsibilities (Timutimu-Thorpe, 1994); whereas, in European (Pākehā) families the individuality of each family member is given priority and there is no formal expectations from the siblings unless they choose to do it of their own free will. Conversely, another powerful impact of the social structures such as arranged marriages in India is that, even where the siblings are willing, they might not be allowed to help their disabled brother or sister if their partner or in-laws do not agree. Thus, social structures can act both as help and hindrance in gaining the long-term support of other family members.

**Shrinking family and community spirit**

Many parents of both groups were also of the view that the people are too busy in contemporary society and hence informal support is not as readily available as it used to be. They felt that the people had become more self-oriented and the community spirit of earlier days was lacking in modern society. On similar lines, some Delhi parents suggested that the informal support that used to be readily available until the recent past under the joint family system was now difficult to get as more and more families were becoming nuclear and physically distant. It has been suggested that the situation in which the Indian families find themselves now with a diminishing joint family structure has been prevalent in the developed world for a long time. “At the same time that the need for family caregiving is increasing, the demographic makeup of families has undergone extensive change. Historically, families have grown smaller over the past century, leaving fewer individuals available to provide care” (Singer et al., 2012a, p. 15). Pinto and Sahur (2001) identified the increased influence of the Western world as a key factor responsible for the shrinking of the Indian joint family system alongside other factors such as industrialisation and urbanisation. With regard to its impact on the lives of disabled people and their families, Singh and Dash (2014) pointed out that, “with the current trend towards a shift from joint family to nuclear families, the fear of parents for proper care of their children with disabilities after them has become an onerous challenge” (p. 37).

Broadbent (2003) argued that when the natural support of the close family is not available to share the caregiving responsibility, the families tend to rely more on the formal support provided by the state. However, the Indian families of disabled people are facing a “double whammy” in this regard as, whilst the informal support that used to be readily available under the earlier joint family system is now reducing, the state of
the formal support services still remains abysmal. In summary, the informal support of
the extended family and the community has become a rare commodity in recent times in
both the developing and the developed world.

The available literature suggests that a number of factors are responsible for a lack of
community kinship with the economic factors and the welfare state being the major
culprits, particularly in the developed countries. According to Shakespeare (2014),
“Western societies became increasingly individualised and atomised during the
twentieth century, as traditional ties of family, religion and community declined. A
range of social, economic and demographic factors reduces the strength of networks of
kin, friends and community” (p. 194). In a New Zealand based study, Lawrence and
Alam (2000) also found that evidence of support from the extended family was reducing
in the contemporary society. Referring to the question (central to this study) faced by a
majority of the parents of children with high support needs – what would happen to my
child when I am no longer alive – Morgan (2009) argued that:

In some ways the question is more difficult to deal with today than it was in past
decades when we knew that we couldn’t depend on government interventions to
the degree we expect today. Friends and families were more comfortable making
commitments to be there when we could no longer take care of our loves ones.
Now everyone has busier lives, and we are such a mobile society that family
members may live so far away they never really get to know your adult child.
The situation becomes more complicated. There are some government programs,
but never enough to meet the needs of all of today’s adults who experience
disabilities. (Morgan, 2009, p. 19)

Linking this argument to our discussion in Chapter 3, it appears that the welfare state
has potentially negative impact on both the personal responsibility of the families and on
the collective community responsibility of looking after more vulnerable populations of
our society. As Lawrence and Alam (2000) explain:

Welfare programmes have tended to impair human character. Instead of
appealing to people’s strengths, the welfare state panders to their weaknesses.
The welfare state has diminished opportunities for people to be of service to each
other, encouraging us to look outwards to “the authorities” instead of inwards to
our own strengths and skills. (Lawrence & Alam, 2000, p. 186)
Further, in the triangulation chapter we also argued that marketisation of services turns both care and the carer into “commodities” that can be bought and sold. This in turn, changes the nature of relationship between the carer and the care recipient and also influences what people do for each other in a natural relationship. As briefly touched upon in the desired future section, even my study indicated that the differences in access to formal support impacted upon the level of personal responsibility that the parents from each group were willing to take, with the Auckland parents expecting the government to shoulder the primary responsibility for the welfare of their children or paying people to look after their own family members. A couple of Auckland parents, however, were of the view that expecting the government to provide for everything was not helpful and that the families should take some personal responsibility for their children:

She is our daughter – she is our responsibility number one – we are the prime carers and the prime people responsible for her. We need to front up to those responsibilities. I am aware of the parents of kids who feel that the world owes them something because they have this disabled child, and no that’s not my view at all. (Russell, Auckland parent)

Some people make it their career to get everything out of the system. Which is the bad side of the story. (Joanna, Auckland parent)

Thus, based on the discussion in this section, whilst it appears that, by and large, the welfare state impacts upon people’s willingness to take personal responsibility towards their own family members, it needs to be recognised that dependency on the state often becomes inevitable for many families of people with HCN. As argued in the triangulation chapter, often one or both parents have to stay home to look after the child with HCN which results in reduced family income. That, combined with the additional costs associated with the child’s impairment puts significant financial pressure on the family. This often does not leave any other choice for these families but to look towards the state for support even if they were willing to take personal responsibility. Further research with a specific focus on the impact of the welfare state on the families’ personal responsibility towards supporting disabled members of their family could shed more light on this debate.
Physical and attitudinal barriers in the community

Communities comprising neighbourhood, local clubs, religious groups, NGOs, private businesses and the members of the public in general could potentially act as a source of informal support for all families. However, as discussed in the previous section, such support is not as readily available in the contemporary society as it used to be because people are generally busier and have become less sensitive towards others’ needs. When it comes to disabled people and their families though, the attitude of the general public acts as another major barrier to their receiving support from the community. As detailed in the societal attitude section of the Findings chapter, many parents felt that society, by and large, still had negative attitudes towards disability and as a result they either avoided contact with disabled people and their families or approached them with a sympathetic or patronising attitude.

The literature suggests that this is an age-old global issue faced to a greater or lesser extent by disabled people and their families living in all countries – rich or poor, developing or developed. Beatson (2004) reported that disabled people found the attitudes of the able-bodied people very disabling. Similarly, in a recent project focusing on acceptance of disabled people in society, the participants reported being made fun of, called names, mocked, being judged, and seen as different due to the labels and stereotypes associated with disability (New Zealand Convention Coalition Monitoring Group, 2015a). Moreover, negative attitudes and the behaviour of the public have also been identified as the key barriers to effective community participation for disabled people (Hatton et al., 2004; Milner & Mirfin-Veitch, 2012; Ministry of Health, 2016a; Wilkinson-Meyers et al., 2014). Kendrick and Hartnett (2005) warned that people’s attitudes and beliefs towards disability could also lead to ill treatment of disabled people because “hurtful thoughts can quickly lead to hurtful deeds” (Kendrick & Hartnett, 2005, p. 36).

The Indian literature suggests that stigma and uncharitable attitudes towards disabled people are still dominant in Indian society (Chakravarti, 2008), and that the community attitude continues to be a major barrier to increasing the profile of disabled people (The World Bank, 2009). In a study with a specific focus on the attitude of the Indian public towards disabled people, Siperstein, Sugumaran, Bardon, and Parker (2004) found that a majority of Indians believed that people with an intellectual disability should not be included in society because they either perceived them to be less capable of ordinary
social interactions or they were uncomfortable with their presence in the community due to religious or cultural beliefs.

As warned by Groce (2005), “Ethnic Heritage is not a Diagnostic Category. No ethnic background wholly explains the way any individual or family will think or act” (p. 2). Further, “Variations Exist Within Groups….All but the smallest cultural groups are further subdivided along socioeconomic, educational, caste, and class lines” (Groce, 2005, p. 2). When it comes to understanding and viewing disability, these variations play a significant part in how disabled members are treated and supported within these groups and sub-groups.

Ultimately, it is the individuals with disability and their families who must decide how disability will be defined and dealt with in the context of their cultural heritage, the rehabilitation service system, and the support mechanisms that exist and must be accessed. (Groce, 2005, p. 13)

The influence of religious and cultural beliefs on social acceptance of disabled people was also raised by a number of participants of my study. When discussing society’s attitude as a separate question, the parents talked about cultural differences in acceptance of disability and suggested that in the cultures with high stigma associated with disability, getting the informal support of the community becomes all the more difficult. Disabled people were also likely to face more discrimination in such societies. For example, the Christian community views disabled people as “reflections of God’s image and as deserving of equal treatment in regard to human rights” (Kim, 2001, p. 254); whereas, many Hindus believe that “disability is due to the ‘sins’ of disabled people or their parents and hence deserved in large measure” (The World Bank, 2009, p. xv). The followers of Buddhism and Hinduism also believe in the concept of karma, “a belief that one’s present life is determined by what one has done, right or wrong, in a previous existence. Thus, followers will accept a perceived misfortune, such as a disability, as predestined” (Sotnik & Jezewski, 2005, p. 27). Social exclusion faced by disabled people and their families due to the Hindu philosophy of karma and disability being seen as a result of the sins of the past life is also reported by other writers (Karna, 2001; Siperstein et al., 2004). Unfortunately, many Delhi parents reported that such beliefs are still prevalent amongst Hindus both in rural and urban India.
One of the other impacts of negative attitudes – irrespective of its source of origin (ignorance, indifference or cultural/religious belief) – is that friendliness or kindness shown towards disabled people is often out of charity or pity (Mehrotra, 2011). Disabled people do not like charity because “charity is perceived as both a positive and ‘sweet’ human value and a mechanism of social control and oppression” (Swain et al., 2003, p. 87). It is therefore not surprising that a number of parents from both groups reported that they avoid asking for help as they do not like the idea of someone helping out of a sense of obligation, charity or pity. As rightly pointed out by one of the key informants, aid and charity can never lead to the equality that disabled people strive for.

In addition to the attitudinal barriers, according to the parents, physical barriers such as stairs and inaccessible transport also made it difficult for their children to access other informal support that might be available in the community. Physical barriers prevent many disabled people from accessing private homes or public places which, in turn, reduces their opportunities to meet other people and increase their informal network (Milner & Mirfin-Veitch, 2012). Physical barriers to access have a more severe impact on the social lives of disabled people in India as the public infrastructure including roads, buildings and transport system is, by and large, inaccessible. “There is much evidence, both quantitative and anecdotal to indicate that accessibility for PWD remains a largely unrealized goal in India to date” (The World Bank, 2009, p. xxii). However, even in New Zealand, the built environment has been identified as one of the key barriers to community participation of disabled people, alongside attitudinal barriers (Ministry of Health, 2016a; Wilkinson-Meyers et al., 2014). Further, the physical access needs of the adults with HCN are often ignored even in otherwise accessible environments. For example, a majority of the shopping malls or community swimming pools in New Zealand do not have changing tables for adults.

As a combined result of the physical and the attitudinal barriers, people with HCN lose out on one of the most valuable sources of informal support – the community. Ironically, as discussed earlier in the section covering the significance of informal support, they need the support of the community (members) to access the community (activities and places) but, as just discussed, the barriers to accessing the community (places) deprive them of opportunities to widen their community (of informal support providers). Thus, many disabled people find themselves in what Duggan and Linehan (2013) describe as a “Catch 22” situation whereby “they find it difficult to live independently and engage in
community activities because they have few friends who could support them, but they have difficulty making friendships because they are excluded from their communities” (p. 205).

As described in the previous chapter, when discussing the potential impact of societal attitudes on their children’s social life after parents have passed away, many parents expressed a concern that if the situation does not improve their children would continue to face discrimination in the society and could be deprived of essential leisure, recreation, vocational and employment opportunities. Thus, parents argued for urgent action in the direction of awareness raising in the community. In conclusion, to uphold the right of the disabled people to participate in the community on an equal basis with others, raising community awareness must become a priority agenda for the policy makers of all countries. To put it in the words of Beatson (2004), “get the attitudes right, and the rest would take care of itself” (p. ix).

**Informal support – concluding remarks**

The discussion so far suggests that informal support could potentially play a very significant role in the lives of people with HCN and their families. However, a number of intrinsic factors such as the nature of the impairment and people’s personal/cultural beliefs; and extrinsic factors such as physical and attitudinal barriers and the weakened social fabric make access to informal support difficult for these families. Perhaps, due to the combined impact of these factors, a number of parents and the key informants of both groups felt that reliance on informal support as the primary source of support is both unrealistic and unsustainable in the long run. Due to the prima facie voluntary nature of the informal support, continuity of care is not assured and further, one cannot demand care at a certain time or complain about the care if it is of poor quality. Many parents also felt that a total reliance on the informal network would leave their children at the mercy of others and hence could make them more vulnerable to poor quality care, abuse or neglect. Further, some key informants highlighted that relying on other family members to provide life-long care might create issues in their relationships, they might face health issues, and they might distance themselves from the disabled child as opposed to spending quality family time with them without having the care worries. The participants of some other studies have also reported similar concerns around difficulties with placing a demand for service on informal networks (Lindblad et al., 2007) and the potential impact on family relationships of such an expectation (Bray et al., 2005).
In summary, the findings suggest that, to adequately meet the social and economic rights of people with HCN as prescribed under the CRPD, neither formal support nor informal support could be relied upon exclusively as they both have certain limitations. A more reliable option on a long-term basis could be a combination of formal and informal support with both systems playing their individual parts in supporting people in different areas. This leads us to the next section which discusses the significance of formal–informal interplay in the support of adults with HCN.

7.2.3 **Formal–informal interplay**

There is a plethora of international disability literature that suggests that both formal and informal support systems must work hand in hand for better outcomes for disabled people and their families (Bennett, 2002; Bigby, 1997; Bray et al., 2005; Fletcher, 1989; Hatton et al., 2004). In the National Disability Insurance Scheme currently being rolled out in various regions across Australia it was made clear at the outset that the supports funded under the scheme were not intended to replace the care provided by people’s informal networks (Judd, 2014) and that there was a need to coordinate funded support with natural support (Henman & Foster, 2015). Similarly, the supported self-assessment tool under the MoH’s New Model also requires people to identify both their existing formal support as well as informal support (Ministry of Health, 2016b). The coordination between both formal and informal systems has also been considered significant for the support of people with mental health problems (Leach, 2015) and in the aged care sector (Chan, Anstey, Windsor, & Luszcz, 2011).

Thus, whilst the findings of my study related to the significance of both the support systems in the lives of disabled people and their families may not be unique, this study has, however, highlighted a very important element about the interplay between formal and informal support systems. It has revealed that when it comes to supporting adults with HCN whose parents are no longer alive, one system cannot even deliver the desired outcomes successfully in certain areas without the support of the other system.

**Why formal support cannot work without informal support**

As previously discussed, various support services delivered through the formal system become crucial in upholding disabled people’s right to live and participate in the community on an equal basis with others. Whilst many disabled people manage their own formal support, due to the nature of their impairment, most people with HCN
depend upon others around them to exercise their rights and to access entitlements. So, for those people with HCN whose parents are no longer alive, if they do not have reliable people in their informal network to advocate for them they might struggle to even access appropriate formal support. They would also need the support of the informal network to supervise delivery of the formal services and to ensure the optimum utilisation of, and prevent misappropriation of, their allocated support.

Similarly, as mentioned earlier, people with HCN have extra support needs that require significant additional funding. Due to multiple beneficiary groups putting demands on publicly funded resources, despite its best intentions it becomes difficult for the government of any country to adequately meet all the additional support needs of people with HCN without a significant contribution from people’s informal networks. Such support could come in various forms and may include financial contribution from immediate family members; financial support from philanthropic organisations and private businesses; the altruism of health professionals in either not charging fees for their services or providing treatment at subsidised rates; or an army of volunteers willing to work in the disability sector without an expectation of monetary compensation from the formal system.

Thus, due to their high and complex needs, for the formal system to effectively support this group of people, assistance of people from informal networks becomes inevitable. Let us now discuss the dependency of the informal support system on the formal system.

**Why informal support cannot work without formal support**

The findings of this study suggest that friends, relatives or neighbours are often willing to provide their time to support a person with HCN, particularly in the area of leisure and recreational activities or in emergency situations. However, they might be reluctant to provide such support if it would also involve bearing the associated financial expenses such as the cost of activity fees and transport, or the medical expenses. Thus, to receive informal support in the form of people’s time, a person with HCN would first need formal support in the form of sufficient funding or publicly funded services.

Secondly, as discussed previously, many parents of children with HCN rely upon their non-disabled children or other family members either to take over the full-time caring role or the role of advocating for their children’s rights or helping them access formal services after the death of the parents. However, they would struggle to carry out these
tasks effectively if they do not receive adequate training, do not have access to relevant information or the system remains complex to navigate and administratively bureaucratic. Further, the siblings would also struggle to make any ongoing commitment if there was no assurance of support from the formal system in the form of adequate respite care for them or other forms of support that would help them continue pursuing their careers simultaneously.

Finally, the NGOs working in the disability sector in India get the support of the parents or other volunteers who are willing to give their time for free. However, without adequate funding for training or the government funded training programmes, these organisations struggle to train this workforce of volunteers and, as a result, struggle to provide good quality care. Thus, for people from the informal network to effectively support people with HCN, their willingness to help and good intentions alone would not suffice and they would need adequate support from the formal system every step of the way. In a nutshell, when it comes to supporting a person with HCN to live a good quality life it is not only imperative that both formal and informal support systems play their parts but, at times, the very success of one system depends upon the corresponding support of the other system.

7.2.4 Desired supports – concluding remarks

This section discussed the parents’ views on the role both formal and informal support could play in their children’s lives when parents were no longer alive and also highlighted various issues with both the systems that impinged upon their children’s right to adequate support and having a choice when receiving those supports (refer to Figure 3). Whilst the negative attitude of the state and economic considerations were the major factors leading to a number of other issues with formal support; physical and attitudinal barriers in the community and a weakened social fabric made it difficult for families to access informal support. Finally, this section highlighted the importance of the interplay between (and the interdependence of) both formal and informal support systems for successful delivery of holistic care to people with HCN. The next section discusses the changes that the parents wish to see happen during their lifetime for them to be assured about their children’s good future after they themselves pass away.
Figure 3.

Summary of Findings: Desired Supports
7.3 Desired changes

Whilst the earlier sections on “Desired future” and “Desired supports” focused on the two key research questions of the study, this section primarily focuses on the research aim of making useful recommendations for design and delivery of disability services that could cater to the specific support needs of adults with HCN and their families. To that end, this section combines the information presented in a number of different sections of the Findings chapter including the section on desired changes, all the sub-sections of the section entitled “Most important responses,” and the parents’ suggestions on improving access to formal and informal support. There was significant overlap in the information provided by the parents under all of the above sections and hence their suggestions are summarised in this section under some key common themes that emerged. At a macro level, all the changes proposed by the parents could be divided into two broad categories: a) actions that the parents needed to take themselves; and b) actions that the parents expected the government to take. Hence, the discussion in this section is presented under the two separate headings titled “Key messages for the parents” and “Key messages for the state.” Within each heading, the changes proposed by the parents are further categorised under various sub-themes.

7.3.1 Key messages for the parents

When asked to share their views on the changes required to their existing support mechanisms for their children’s future beyond the time of parents’ death, many parents seemed to have given it serious thought and offered a lot of ideas and suggestions including on what succession planning they needed to do secure their children’s future. However, there were also some parents who had not thought much about the future as they intended to carry on their role for as long as they could. Some felt that it was too early for them to start planning and some even talked about leaving things to destiny.

To a certain extent there are things that can’t be decided right now. I am not dead yet. (Donna, Auckland parent)

I allow the universe to unfold. I can’t plan too much because I have realised that the best plans get made somewhere else. (Kanchan, Delhi parent)

Lack of planning on the parents’ part or even a reluctance to engage in planning has also been reported in many other studies (Hatton et al., 2004; Redmond & Richardson, 2003; Taggart et al., 2012). So before we talk about the changes proposed by the parents, it is
important to briefly touch upon the reasons why certain parents avoid succession planning – that is, preparing for the future of their disabled children after the parents have died. During their review of the relevant literature, Taggart et al. (2012) found that:

Carers may not make plans as a result of denial about the inevitability of their own mortality and the realisation that they will not be able to provide care indefinitely. Moreover, they have difficulties in letting go of their loved ones as it may mean increased loneliness for them and an end to their role in life. Also carers may harbour deep concerns and anxieties about what will happen to their relative in alternative out-of-home placements. They find the subject too painful to broach and do not make firm plans until it becomes unavoidable. (Taggart et al., 2012, p. 219)

Thus, many parents avoid future planning as it is a very sensitive topic that might force them to face a lot of their own mental insecurities, anxieties or inhibitions. However, whilst a reluctance to plan on some parents’ part might be understandable, the literature suggests that it is certainly neither advisable nor desirable to delay the planning until it reaches a point of crisis. The potential dangers of a lack of timely planning include the adult child not acquiring the necessary functional skills to be independent (Shaw et al., 2011); the child being forced to move to an institution and/or live a diminished quality of life (Broadbent, 2003); emotional trauma and unexpected dilemma for the family and a sudden demand placed on the formal support system (Taggart et al., 2012). Further, if the parents do not make their and their children’s wishes explicit to others in a timely manner, the future decisions taken by others might not be in the best interest of their child. Thus, it becomes important that the parents do timely succession planning.

Moving on to the information shared by the parent participants who had started to think about their children’s future, the key themes that emerged from their suggestions around succession planning are now discussed. It should be noted that, in addition to the parents’ ideas on what they would do for their own children, the discussion here also includes their suggestions for other parents of adult children with HCN. In other words, the headings below could also be read as the key messages from the parent participants of my study to other parents in a similar situation to theirs.
**Prepare the child**

In most cases, people with HCN living at home are completely reliant on their parents for every aspect of their life and hence they share a unique bond with each other. Read (2000) argued that sometimes, there could even be a power imbalance in the parent–child relationship due to the child’s total reliance on the parents, particularly on their mothers.

It can be argued that the power relations between mother and child are unequal and that it may be mostly in the hands of the mother to decide what is in the interests of her child and what can realistically be achieved. This may be particularly the case when a child’s or young person’s ability and opportunity to communicate with and through others is limited. Such young people may be reliant both upon their mothers’ interpretations of their needs and their willingness to follow them through. (Read, 2000, p. 113)

Given such an important role of the parents in their adult children’s everyday life, it would undoubtedly be extremely difficult for the children to live without their parents. Hence, it is not surprising that many parent participants of my study suggested that, first and foremost, what they would need to do is to prepare their children to live without them. Perhaps recognising the difficulties with mentally preparing their children with HCN to live without them, many parents felt that they could at least start training their children in such a way that they gradually become less dependent upon them for their various support needs. In this regard, a couple of Auckland parents and many Delhi parents talked about training their children in looking after their own personal care needs and doing some household chores. Some Auckland parents also talked about increasing the frequency of sending their children to a respite care home so that they gradually get used to the idea of not having the parents around 24x7. Further, given their grave concerns around potential abuse, some parents also talked about somehow helping their children understand what abuse looks like and what to do if it ever happened. Finally, some Delhi parents talked about sending their children to a day centre where they could learn some useful social, artistic or vocational skills with a view to helping them build relationships with others and also potentially earning some income and reducing their financial dependency on them.
For all of the above to happen, firstly the parents would need to believe in their children. Unfortunately many parents underestimate their children’s abilities and, as a result, have very low expectations of them. It has been suggested that this could often be the result of internalisation on the parents’ part of the negative attitudes of the community towards their children and in turn could reinforce their dependence and social marginalisation (The World Bank, 2009). Therefore, it is vital that the parents approach this task with a positive attitude and invest time and efforts in recognising their children’s skills and abilities. At the same time, it is also important that they be realistic about their expectations and do not have false hopes around the level of independence that their children could practically achieve.

**Prepare the informal network**

In addition to preparing the child, many parents also talked about preparing their informal network of family and friends in supporting their children after the parents’ death. As previously discussed, parents play multiple roles in their children’s lives and when parents are no longer there, it might be necessary or even desirable to share those roles between different people. In this regard, the parents identified a need for talking to their immediate and extended family, friends and relatives at an early stage about who would play what role in their child’s future and understanding what support they would need in carrying out their respective roles. In terms of concrete actions, the parents’ suggestions around preparing the informal network included identifying potential successor/s; appointing welfare guardian/s; creating a circle of support; and providing training to all concerned.

**Identify potential successor/s**

Finding someone who could take over the direct care or the oversight of the formal care of their children was reported by the parents of both groups as one of the top three changes that would help them die peacefully. Whilst a majority of the parents expected their other, non-disabled, children to be their successors, some Delhi parents suggested that their own younger siblings might take over that role. A couple of parents were, however, of the view that ideally the parents should hand over the reins to someone of more or less similar age to their disabled child for long-term continuity of care.
Appoint welfare guardian/s

To support their children with decision making and/or financial management, many parents talked about either setting up a trust and/or appointing someone as a legal welfare guardian for their children. Whilst some parents suggested that their successor would also become their child’s welfare guardian, some talked about having multiple people involved in this role. Finding the right people for this role who have a good understanding of their children’s needs and preferences could help parents alleviate some of their worries around decision making and potential financial exploitation.

Create a circle of support

Many parents also recognised a need for helping their children develop relationships and widening their children’s social network as part of the succession planning. The parents’ suggestions in this regard included gradually increasing their children’s social interaction with family, friends, relatives, and wider community; joining family support groups; or starting an informal club in their own house:

If I could get similar minded interested people who would come with their support workers and come and spend just one hour in his garage where people like him can come and spend a little time. You know just for plain recreation. It’s supervised – we are there. Their parents can come, so a little club can start. (Mrs D’souza, Auckland parent)

Creating a circle of support around the child could be helpful in a number of ways including assisting at times of emergency, in keeping the person safe, providing emotional support and avoiding issues associated with isolation and loneliness. Taggart et al. (2012) also suggested that the concept of circle of support or a “circle of friends” comprising family, friends and the members of the community could be particularly helpful for the social well-being of people with an intellectual disability or high support needs. Further, the literature also suggests that, where such supports are not naturally available to parents, they might need to be facilitated through professional help (Duggan & Linehan, 2013; McCallin et al., 2007; O’Brien, Thesing, & Capie, 2005). As Morgan (2009) warned, “loneliness is the only real disability” (p. 27) and hence it becomes vital that the parents take appropriate measures to help their children develop long-lasting social networks, friendships and relationships.
**Provide training**

Finally, as part of preparing the informal network to provide adequate support to their children, it would become vital for the parents to train their successors, future guardians and all the other people who become part of their children’s circle of support. The successors might need specific training in how to provide personal care and health care related needs, whereas welfare guardians or trustees might need briefing on their children’s entitlements to various services and navigating the formal system. However, all people in the child’s informal network would need training in non-verbal communication irrespective of the role they play. The parents need to train people in how to communicate with their children with a specific focus on the various signs, gestures and behaviours they use for communicating their needs and preferences. This would also increase the chances of their children continuing to have a say in what happens in their lives when parents are not around. As previously mentioned, the parents are the best experts when it comes to supporting their children with HCN, and hence it becomes vital that, wherever possible, the parents provide this training themselves to all concerned whilst they are still around and able to do so.

**Sort out the living arrangements**

Sorting out the living arrangements for their children was also reported by a majority of the parents from both groups as one of the three most important changes that would help them die peacefully. In terms of concrete actions, depending upon their preference for future accommodation type, the parents talked about checking out the suitability of the available residential options for their children; buying or renting a house, transferring the house to their disabled child’s name or in joint names with their other, non-disabled, children. One Auckland parent suggested that given the shortage of suitable residential options that cater to the specific support needs of their children, the parents need to be a bit more realistic in their search for out-of-home options and that they should also be willing to make some compromises.

One of the things that I keep telling myself and my family that initially we were looking for a perfect place for Maria – we let “perfect” get in the way of perfectly adequate. So, if we look for perfect – it won’t happen; if we look for something where most of the boxes are ticked – we will find something. So we will have to make some compromises and some adjustments. (Mr Smith, Auckland parent)
Secure the financial future

Some Auckland parents and almost all the Delhi parents felt that, in addition to sorting out the living arrangements, they would also need to do something about securing the financial future of their children as otherwise their children might end up living at the mercy of others. The concrete actions that the parents felt they needed to take in this direction during their lifetime included preparing a will, putting some funds in the child’s name, getting assurance from other family members of their ongoing financial support for their children, setting up a small family-run business in the child’s name, or working with the government to ensure that their children would continue to receive adequate lifelong financial support. As previously mentioned, a majority of the Auckland parents (including those who were financially affluent) expected the state to take full responsibility for their children’s future financial needs.

Create a life plan and a training manual

Whilst we touched upon the need for the parents to train the people in their informal network, a number of parents felt that it would be crucial that even the support staff from the formal system have access to their knowledge of their children’s needs. Many parents talked about creating a life plan for their children detailing their support needs, likes and dislikes, and goals and aspirations. This would ensure that, irrespective of the changes in who provides the support, their children’s needs and preferences would be known to all even when parents were not around to advocate for them. A couple of parents of children with complex medical conditions suggested that along with the life plan they would also need to create an instruction/training manual providing minute details of their children’s health and personal care needs and how to meet them. Such a manual could also include pictures and/or videos of parents doing the care themselves so that others would know what exactly needs to be done and how; the details around their children’s preferred method of communication and what different signs and gestures mean; their memorandum of wishes; a note on their values; and a list of “dos and don’ts” important for ensuring the safety of their children.

Yeah, it would be like me leaving a manual of me behind [laughs]. So that the next person whoever I would like to take over the guardianship would know my core values. (Louise, Auckland parent)
One Auckland parent had already prepared such a manual and presented a brief description of the manual in the following words:

There is a fifty page training manual which spells out how to assist me with my health, how to assist me with my mobility, how to take me out to cafe, it also has a whole lot of background knowledge such as who is who in her family, because being non-verbal often you have to initiate the conversation. Lot of photo books and albums, so people can look through that and say ohhh this is so and so – that sort of thing. (Rosemary, Auckland parent)

**Prepare the community**

Finally, given the negative attitudes amongst many members of the society towards disabled people, many parents felt that they also needed to be proactive in preparing the community to accept their children:

We may have to battle at different levels right from our neighbours to community to government to organisations to doctors. But we should try and give our kids whatever they need – fight for their rights. (Sunita, Delhi parent)

According to some parents, one of the best ways of educating the community about their children was taking them out wherever they went and approaching members of the public with a positive attitude rather than a feeling of shame or embarrassment. In many parents’ experience, the public generally reciprocated the feelings and hence a positive attitude was more likely to be reciprocated by positivity and acceptance in return. The parents could also educate the community by getting involved in various awareness raising programmes about their children’s (dis)abilities. Some Delhi parents shared positive experiences of conducting flash mobs in public places and having exhibitions of the products prepared by their children. Many parents, however, felt that to bring about a change in community attitudes, it was important that the families checked their own attitude first and changed it, if required. Their suggestions for other parents included accepting their children, believing in their abilities, and loving them for who they are.

**Concluding remarks**

This section discussed the parents’ suggestions on some of the actions that they could take themselves to help address some of their worries and the issues with informal support as highlighted in the previous sections of this chapter. A majority of the parents were aware of the mammoth challenge that lay ahead of them in terms of preparing for
their children’s long-term future beyond their own lifespan. Whilst some parents were more proactive and had started to gradually put things in place, some others had not thought much about it or did not know how to go about it. It has been, however, suggested that the parents do not need to do it all alone and the government must provide the parents with appropriate professional help in succession planning (McCallin et al., 2007; Taggart et al., 2012). Many parents in my study, too, provided similar suggestions to other parents around looking after themselves and seeking professional help, where needed.

Don’t make a martyr out of yourself. If you need a hand, stick your hand up and say I need a hand, because you are not going to do anybody any favours.
(Wendy, Auckland parent)

Just make sure that you look after your own health and not just your physical – your spiritual and your relationships – very important. (Joanna, Auckland parent)

As reported by Taggart et al. (2012), there are a number of successful educational programmes such as “Future is Now” in UK and “Safe and Secure” in Canada designed specifically to assist ageing parents and their supporters with succession planning. The New Zealand and the Indian governments could develop similar programmes relevant to their local context to assist the families of children with HCN with succession planning. This leads us to the next section on the role of the state in creating a better future for the children with HCN whose parents are no longer there.

7.3.2 Key messages for the state
The parents of both groups felt that the state would need to play a major part in providing a happy, comfortable and safe life for their children once they were no longer around. However, as discussed in the Desired supports section, the issues highlighted by the parents with their respective formal systems impinged upon their children’s right to adequate support and they were also a major cause of many of their worries listed under the Desired future section. Therefore, their responses to the questions around improving formal support and the suggestions they had for the policy makers and funders primarily revolved around the actions they wanted the government to take to resolve the existing issues with the design and delivery of the services for their children. This section, therefore, summarises the parents’ suggestions under various key themes and links them with the issues identified in the previous section. The discussion is supported by the
information shared by the key informants, international literature and the findings of other relevant studies. References are also made, where appropriate, to relevant articles of the UNCRPD to situate the discussion within the rights, choice and supports framework. Finally, whilst this section discusses some specific implications for India and New Zealand, overall, it has global implications for policy, practice and research.

**Change attitudes**

As discussed previously, according to the parents as well as the key informants, the negative attitude of the government towards disability and disabled people was the primary cause of many issues they faced with the formal support. Therefore, they were of the view that, for any positive change to happen in the direction of improved services, first a change would be required in the attitude of government officials, right from the people doing the assessment of the needs to the policy makers and the politicians of the country. A couple of Delhi key informants mentioned that there was a lack of awareness and *sensitisation* amongst the people working at this level.

The Auckland parents and the key informants were particularly vocal about the government’s attitude and suggested that considering any beneficiary group as a “cost burden” on the economy was not particularly helpful as it impinged upon their rights.

> If we class ourselves as a civilised community you got a couple of options. In this community your option is either you eradicate these people at birth so they are not a burden on your society or cost to your society and that is not acceptable. If that’s not acceptable then it is going to become a cost to our society like putting down the roads, laying electricity cables and looking after these people because there comes a time where the existing caregivers – the parents – can no longer do the job. (Mr Smith, Auckland parent)

> I just think we have come a long way but we have a hell of a way to go. The reality is that the people you are talking about are really the pointy end of – they are the hard cases to deal with, and that if we are going to go with them in a way in which acknowledges their humanity and their human rights as printed in the CRPD – it’s going to cost money. And the state has to be prepared to spend that money. (Mr M, Auckland key informant)

Ms L, another Auckland key informant, suggested that the government needed to change its mentality from a “welfare” approach to one of “investment” when it came to
supporting disabled people. She felt that providing formal support was about investing in someone’s quality of life because in the long term the care could become less expensive as either the person would live a happier and healthier life or could potentially also become a contributing member of the society.

Similarly, advocating for the need for a change in the “expert” mentality on the part of the senior government officials, one Auckland key informant expressed his frustrations in the following words:

Politicians and policy makers and bureaucrats and service providers, damn it, come to it thinking that what I know now is all there is to know. So my idea is the idea, and in no other field could you come with a level of ignorance that people come into this [disability field] at senior levels and decision making levels and really know nothing about what they are doing. And you just let them manage budgets and stuff like that [laughs sarcastically], it’s outrageous really.

(Mr J, Auckland key informant)

Thus, a major attitudinal change on the government’s part would require an acknowledgement that disabled people and their families are the real experts on their own lives and hence they must be consulted with for all decisions affecting their lives.

Provide adequate funding and services
As discussed previously, people with HCN have certain unique support needs and to meet those needs adequately they require additional funding and services. Many parents from both groups were of the view that the government must recognise the unique support needs of their children and that the funding allocated to them and the services designed for them must take into consideration their extra support needs in all areas. Let us now discuss some of the specific suggestions of the parents for the government with regard to better supporting their children in various aspects of their life.

Residential services
The actions that the Auckland parents wanted the state to take in relation to providing better residential support to their children included developing more age- and impairment-appropriate residential options that could cater to the specific support needs of their children; assisting the parents in procuring affordable accessible homes for their children; and providing better support to other family members in continuing to care for their children at home. These proposed changes align with the state parties’ obligations
under UNCRPD Article 19(b) – to provide a range of residential services; Article 28(2)(d) – to provide access to public housing programmes; and Article 23(5) – to provide alternative care within family (UN General Assembly, 2006).

A majority of the Delhi parents, on the other hand, suggested that the government should open more residential homes as, for many parents, particularly those from lower socio-economic backgrounds, their primary concern was meeting their children’s need for a shelter after the parents are gone. Given our previous discussion around the size of some of the residential homes in India, including the institutional model of their operations, this suggestion of the parents requires further discussion in the context of rights based framework. Article 4(1)(d) of the Convention places a general obligation on the state parties to “refrain from engaging in any act or practice that is inconsistent with the present Convention….” (UN General Assembly, 2006, p. 5). As discussed under the section on issues with formal support, a number of practices that go on in large residential facilities such as minimal services, lack of choice, and power imbalance between the residents and staff are contradictory to the very purpose of the Convention of promoting and protecting the fundamental human rights of all disabled people (UN General Assembly, 2006). Further, such practices also impinge upon a number of the individual rights of the residents including their right to liberty; freedom from inhuman treatment and punishment; and freedom from exploitation and loss of personal integrity (UN General Assembly, 2006). Therefore, being a signatory to the Convention, the Indian government must work on a war footing to close down the remaining large institutions and work towards creating smaller residential homes in the community.

As mentioned in Chapter 4, the National Trust’s new group home scheme, Gharaunda, prescribes the maximum limit of 20 residents per home (The National Trust, 2017a). Whilst this limit is still on the higher side, considering the size of the population requiring such facilities, the scheme is nevertheless a positive step in the direction of providing better housing options to people with HCN. Efforts must be taken to promote and extend the Gharaunda scheme widely across all the regions of the country and it should also be ensured that the focus of such homes is not only on meeting the basic care needs of the residents but also on providing them a good quality of life.
Health care

With regard to improving health care services for their children with HCN, the Auckland parents highlighted a need for better education of the health professionals in understanding the specific conditions of their children; better coordination between the professionals during the transition of their children from paediatricians to adult health services; and more funding for personalised aids and equipment and behaviour management support for their children. The changes suggested by the Delhi parents, on the other hand, included providing free basic health care closer to home, their children receiving priority treatment to avoid having to wait in queues, and free medical insurance. The changes proposed by both groups of parents align with the state parties’ obligations under Article 20(b) – to facilitate access to mobility aids and equipment; and various sub-articles of Article 25 – to ensure access to appropriate health services (UN General Assembly, 2006). Many adults with HCN in India would be eligible for the National Trust’s health insurance scheme Niramaya (The National Trust, 2017b). This scheme should be well promoted and extended across all the regions of the country on a priority basis.

Day services and vocational support

Regarding improving the social and vocational life of their children, the parents of both groups talked about a need for more day centres equipped to provide leisure and/or vocational activities suitable to their children’s (dis)abilities and interests; and providing better access to community based activities. Some Delhi parents specifically suggested that the day/vocational centres should help their children pursue their hobbies and learn necessary skills to turn those hobbies into a potential source of income. This suggestion from the Delhi parents aligns with Article 30(2) of the Convention which proposes that the “States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society” (UN General Assembly, 2006, p. 22).

It is important to note here that, whilst both countries do have day/vocational centres or some community based activities for disabled people, they are often not equipped to meet the specific support needs of people with HCN. Article 19(c) specifically mentions that the community services and facilities need to be responsive to the needs of its users (UN General Assembly, 2006). Thus, the operators of such programmes and activities
need to employ suitable support staff and be more creative in better accommodating people with HCN in their services. Further, involvement of the parents and other family members could be particularly useful in designing physical layout as well as activities that would suit the needs of people with HCN. In India, the National Trust’s day care scheme, Vikaas, is a positive step in the direction of increasing the number of day/vocational centres, however, they must ensure that the specific needs of people with HCN are catered to in these centres.

Many Delhi parents and a couple of Auckland parents also suggested that the government should either provide suitable jobs for their children or support them with some form of self-employment. In this regard, a number of Delhi parents mentioned that they did not mind even if their children were not paid or received a low level of remuneration for their work at vocational centres (also often known as “sheltered workshops”) because they believed it would still keep them occupied during the day and more importantly it would be helpful for their self-esteem as they would have a feeling of doing something worthwhile.

We wish that he should be employed in some work. Otherwise how will he spend his whole day. (Mr Shah, Delhi parent)

That way, the kids can be busy through work – it could also be done as a social work without pay. (Gita, Delhi parent)

Since the advent of the UNCRPD, in many developed countries, including New Zealand, the concept of sheltered workshops employing disabled people on petty wages has been abolished on the grounds of discrimination against disabled employees as such practice contravenes their right to just conditions of work on an equal basis with others as prescribed under Article 27(b) of the Convention (UN General Assembly, 2006).

In India, however, there are still a number of vocational centres that sell articles made by disabled people attending their centres. Some centres pay their disabled workers and some do not; and sometimes even within a centre some people get paid and some do not depending upon their individual contribution to the final product. Based on what my study participants told me and my personal experience of visiting a couple of such centres during my fieldwork, many disabled people and their families seem comfortable with such an arrangement. They appear to have adopted a more pragmatic approach towards this issue by giving weighting to the other, non-financial, benefits of attending
such centres such as gainful occupation, increased social interaction, and a sense of self-worth from doing some productive work. This, however, poses a significant challenge to the Indian government as allowing something to continue that seems to work for some disabled people and their families is in reality against their obligation as a signatory to the Convention. Further research exploring the views of the parents of adults with HCN living in New Zealand and/or other developed countries around such a pragmatic approach to this issue could shed more light on this debate.

Financial support
In relation to the future financial security of their children, the Auckland parents’ suggestions included increasing funding to adequately meet all the extra disability related costs and to cover the transport costs and activity fees so that their children could attend community based activities. On the other hand, the Delhi parents, particularly those from lower socio-economic backgrounds, urged the government to provide regular financial support – adequate enough to meet at least the basic survival needs of their children. Previously, we have already discussed that the amount of disability pension in India differs from state to state and is grossly inadequate to meet even the basic needs of food, clothing and shelter. To fulfil their obligation under Article 28(1) of the Convention to provide an adequate standard of living to disabled people and their families, the central government of India must take a more proactive role in providing some standards or guidelines around the amount of pension offered by the different states across the country. Besides, the pension offered to people with HCN should consider the extra expenses associated with their disability and hence should be correspondingly higher than those with lower support needs. Other suggestions from the Delhi parents with regard to financial support included basing the pension amount on the financial situation of the individual families, and offering special tax rebates to the earning members of such families in recognition of the extra financial demands on the family due to the child’s disability.

However, empathising with the government’s position around having to meet the needs of multiple beneficiary groups in such a hugely populated country, the Delhi parents as well as the key informants suggested that they realised the government’s limitations but hoped that the government would do more.
I can understand the situation of the government too. I know how I run my own home whereas they have to run the entire country. So they can’t do everything. I sometimes wonder how they will be sleeping at night. (Mahesh, Delhi parent)

Suppose the New Zealand model is implemented here, the government will go bankrupt [laughs]. (Mr E, Delhi key informant)

In summary, the parents of both groups suggested that their respective governments needed to make a number of changes in relation to improving various services and the financial support offered to their adult children as they had higher support needs. Referring back to our discussion in Chapter 3, adopting Fredman’s concept of “substantive equality” (Fredman, 2005) could be particularly helpful in supporting people with HCN. It recognises the diversity within minority groups and proposes that the concept of equality should be reconfigured to consider the relative differences in people’s needs. Accordingly, all disabled people having equal rights does not mean that they get equal support but get supported according to their own unique needs so that they could live and participate in the community on an equal basis with others. Thus, states need to acknowledge and realise that supporting people with HCN might require significant additional funding and services commensurate to their needs. To put it in the words of Shakespeare (2006), to uphold the right of the people with HCN to live and participate in the community on an equal basis with others, “creating a level playing field is not enough: redistribution is required to promote true social inclusion” (p. 67).

Provide the necessary support to the successor/s

As mentioned previously, when it comes to people with HCN, not only the disabled person themselves, but the entire family should be well supported because the social and emotional costs of inadequate support could be very high. Many Auckland parents in this study were of the view that it would be crucial that the government continued to provide the support that they were receiving from the formal system to their successor/s (be it the child’s siblings, or other family members) so that they could effectively support their children in the future. Article 23(5) of the Convention specifically mentions that the “States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family” (UN General Assembly, 2006, p. 16). Hence, to fulfil this obligation, providing adequate support to other family members becomes paramount.
A need for the policy makers and the service providers to understand how best to support the family members caring for their adult disabled children at home has been well recognised in the literature (Bray et al., 2005; Heller & Factor, 2008; Hewitt et al., 2013; Judd, 2014; McCallin et al., 2007; Taggart et al., 2012). In terms of the specific nature of the support, the parents suggested that, given the intense nature of the caring role, the other carers must be offered appropriate respite from their caring roles. The literature emphasises the importance of both informal respite, in the form of shorter breaks (Kersten, Mclellan, George, Mullee, & Smith, 2001), as well as formal respite that gives parents and/or other family carers a few days off at a time at a regular interval to rejuvenate themselves (Bray et al., 2005; Judd, 2014; Singer, Biegel, & Ethridge, 2012b). In addition to respite care, the other support needs of the future informal carers might include financial support (Singer et al., 2012b), information regarding the service entitlements of the person they are supporting (Lindblad et al., 2007), support with planning (Taggart et al., 2012), support with the management of individualised funding and staff recruitment (Henman & Foster, 2015), and specialist training in caring for their family members as well as emotional and practical support. (Te Pou o Te Whakaaro Nui, 2013).

It could be argued that the concepts such as “person-centred care” and “individual quality of life” need to be extended to “family-centred care” (Epley, Summers, & Turnbull, 2012; McCallin et al., 2007) and “family quality of life” (Wang & Brown, 2012) when it comes to supporting people with HCN. A failure to do so might result in having to move the person to a full-time residential placement which often proves costlier than providing adequate support to the family in continuing to look after their disabled family member at home (McConkey et al., 2011). Further, supporting another family member in looking after the disabled person would also alleviate some of the issues around high turnover and inconsistency of care associated with externally paid staff. Singer et al. (2012b) pointed out that “support for caregiving families is likely to remain a prominent concern of the public and policy makers for the foreseeable future” (p. 199).

Since the Delhi parents themselves did not receive any formal support in their caring role, their suggestions for the government primarily focused on the future support needs of their children. Mehrotra (2011), however, alerted that given the decline in the traditional support of the extended family and community members, the government
must turn its attention to the support needs of the families to help them carry on the caregiving responsibility of their disabled children. The National Trust’s respite care scheme, Samarth, and the day care scheme, Vikaas, could assist in providing the families with more formal respite as well as short breaks during the day, respectively.

**Work towards exploring alternative sources of support**

Given our discussion in the triangulation chapter around economic considerations taking priority and the progressive realisation clause of the UNCRPD, it is unlikely at least in the near future that formal support alone would be adequately able to meet all the support needs of people with HCN and their families. Therefore, it becomes paramount that the governments look at alternative sources of support. Recognising the constraints on state resources, one Auckland parent talked about the significance of support of the student volunteers; whereas some Delhi parents and key informants talked about the roles of the voluntary organisations (NGOs) and the private sector in complementing the formal system in supporting their children.

According to Swain et al. (2003), informal support (particularly of the family members), formal support (from the state), voluntary support of charities (NGOs), and the support of the private sector form the four key sources of welfare support. As discussed, in New Zealand, formal support (including the services offered by the NGOs that receive government funding) plays the biggest part in supporting disabled people and their families followed by the informal support, whereas the charities (non-funded NGOs) and the private sector play a very minimal role. In India, however, as elaborated in Chapter 4, besides informal support, the charities play a major role in the support of disabled people and their families (with over 3000 NGOs working in the sector with limited funding) and lately, the private sector has also started playing a role through their Corporate Social Responsibility (CSR) schemes. As highlighted by the World Bank (2009):

> While the public sector will continue to play a critical leading role in disability policy and framework for service delivery and has binding obligations to its disabled citizens to do so, the study finds that it is neither possible nor desirable for the public sector to “do it all”. (The World Bank, 2009, p. xii)

New Zealand could benefit by exploring the ways of increasing the role of the private sector using the concept similar to the CSR in India to cater to the unmet needs of
disabled people and their families through the existing formal system. Further, to attract more private funding to the sector, taxation benefits could be provided to individual donors and philanthropic organisations. The support of the community could come in the form of people from all walks of life providing their time voluntarily or through private professionals and companies offering their products and services voluntarily. As suggested by one Auckland parent, high schools and colleges could provide informal support in the form of encouraging their students to volunteer their time as part of their field education. It could be mutually beneficial to the students as well as the families and it would also not put any additional pressure on the financial resources of the state. Organisations such as Volunteering New Zealand could be of help in this regard. However, it would not be possible for individual families to approach schools, community or private organisations for their support and hence the government must facilitate this process.

The concept of “natural supports” represents the importance of rich and varied social networks, along with engagement and contribution to civil society. It includes the naturally occurring networks we experience in our neighbourhoods, in the wider community through the interests we pursue, and in our working lives. In a disabling society these networks frequently require facilitating, navigating, supporting and, at times, replenishing. (New Zealand Disability Support Network, 2016, p. 14)

The MoH's Local Area Coordination initiative (Ministry of Health, 2016b) is a positive step in the direction of helping the families identify and utilise such alternative sources of support within their local communities. Whilst such initiatives are often viewed and criticised as cost-cutting measures, they could be crucial in complementing the formal support to effectively meet “all of life” and “whole of life” support needs of people with high support needs.

In the Indian context, the NGOs play a significant role in delivering support services in the disability sector often without any government support – financial or administrative. Their success relies on private donations and an army of kind-hearted volunteers willing to give their time free of charge. However, given the minimal reach of formal support to all the families living in different regions of the countries, a need for better partnership between the government and the NGOs has been identified. “A meaningful and robust
partnership is indeed the need of the hour to provide equal opportunities as well as the much required services at the doorsteps of those who are yet to be reached” (Singh & Dash, 2014, p. 103).

**Remove physical and attitudinal barriers from the community**

Many parents of both groups suggested that their children getting accepted by the society and being respected as valued citizens was one of the changes that they wanted to see happen during their lifetime. As discussed previously, the parents identified a number of physical and attitudinal barriers to their children’s access to and acceptance in the community and hence suggested that the government must work towards removing these barriers to facilitate effective participation of their children in the community. The parents’ desire for their children’s acceptance in society is resonated in Outcome 6 (Attitudes) of the NZDS 2016-2026 in the following words: “Disability is understood and accepted as a part of the diversity of the human experience and we are treated with dignity and respect by those around us and society more broadly” (Office for Disability Issues, 2016, p. 34)

In addition to being emphasised in Articles 8 and 9 of the Convention, a need for government action in improving physical access and awareness raising in the community has been identified in the literature of both countries (New Zealand Convention Coalition Monitoring Group, 2015a; New Zealand Disability Support Network, 2016; Singh & Dash, 2014; Siperstein et al., 2004; The World Bank, 2009; UN General Assembly, 2006).

Many parents from both groups suggested that the government must work in partnership with the families, NGOs, and the media for raising community awareness. A couple of Delhi parents and key informants suggested that schools and vocational centres for disabled people can play a major role in changing societal attitudes. These centres often have a lot of visitors coming from various walks of life and provide them with an opportunity to interact with disabled people and see the products made by them. This helps people focus on the abilities of disabled people and, in turn, it helps bring about attitudinal change. Thus, it is important that the awareness raising programmes focus not only on removing negative attitudes but also towards showcasing and promoting positive values. As Kendrick and Hartnett (2005) state, “values that are negative will
need to be challenged in order to be changed, and positive and valuing outlooks will need affirmation and nurturing in order to come into force” (p. 42).

**Enable choice and control**

Earlier it was discussed that, when it comes to people with HCN, people misinterpret their limitations in verbal communication or lack of independence as their inability to make their own choices or decisions. Therefore, a number of Auckland parents identified “an assurance that their children would be able to live a life of their own choice” as one of the three most important changes that would help parents die peacefully. In this regard, the specific changes the parents wanted the government to make included offering more suitable service options so that their children could choose where they live, who they live with, and how they spend their day; making funding more flexible so that they could decide on what they use their allocated funding for; and most importantly, include them and their children in all decisions affecting their lives.

With regard to the first two suggestions of the parents around service options and flexible funding, it needs to be recognised that the various initiatives under the MoH's New Model such as CCL, EIF and supported self-assessment are all designed with the primary focus of offering better choice and control to disabled people and their families (Ministry of Health, 2016b). Hence, it is recommended these initiatives are expanded to all regions of the country on a priority basis. However, as discussed under the section on issues with formal support, it also needs to be recognised that whilst these initiatives are welcomed by some families, others remain apprehensive about the translation of the theoretical rhetoric guiding these models into the practical realities of their children’s lives. Therefore, it becomes important that the families’ apprehensiveness about the benefits of these models and having a concern about their own ability (now and in the future) to manage the funding or monitoring of the services are well supported. Further, as discussed earlier, many people with HCN might choose a residential home over living alone for a number of different reasons. Thus, whilst the policy makers might want to push for the newer independent living models, the traditional residential models must also continue to be offered as an option for those who choose it. Emphasising the need for a flexible approach, the New Zealand Disability Support Network (2016) suggested that the recent focus on supported living option should not “exclude the possibility of people living in small group arrangements – the distinction is about the choice and control people have over if or when this might be an option they wish to pursue, and
with whom” (p. 14). Thus, a range of different accommodation options should be made available so that the families can choose the one most suited to their individual circumstances. However, to ensure that those who choose residential homes still continue to have a reasonable level of choice and control, the issues alluded to earlier regarding set routines and structures within those homes must be given due consideration and the service providers must ensure that those homes are not operated as mini institutions.

Based on our discussion thus far, when it comes to offering true choice and control to people with HCN and their families, it becomes paramount that they get consulted with directly (and not through their able-disabled representatives) to gain a better understanding of their unique support needs. This brings us to the third suggestion of the parents around including them and their children in the decisions affecting their lives. The need for consultation with disabled people and their families to offer them better choice and control over the services they receive has been recognised in the New Zealand literature including various government reports (Ministry of Health, 2014b; New Zealand Disability Support Network, 2016; Office for Disability Issues, 2014).

A detailed discussion on how to appropriately consult with the parents of people with HCN is presented later under the section on parent–state partnership. The rest of the current section, however, discusses the issues surrounding consultation with people with HCN themselves, particularly considering that many of them are often non-verbal. It has been emphasised earlier that all disabled people irrespective of the severity of their impairment and the method of communication that they use should be encouraged and supported in having a say in decisions affecting their lives. For non-verbal people, it would mean that their unspoken words are heard. “Non-verbal people’s voices can be just as strong as verbal people’s voices if people in our society are willing to have patience and listen to non-verbal people” (McMillan, 2016, p. 4). The cry of the non-verbal people for being heard is expressed in “Outcome 6 – Attitudes” of the NZDS 2016-2026 in the following words:

We will be encouraged to speak out in whatever language we use, and our views will be listened to. This includes those of us who may communicate differently, use technology to communicate, and/or have support to communicate or express
our preferences. As a result, we are confident demonstrating the value we bring to our families, whānau, community and the country as a whole.

Our views, either as an individual or as part of a group, will be listened to without being diminished, and society will not seek to take this away, either by accident or design. (Office for Disability Issues, 2016, p. 34)

Some of the crucial components of a supportive design, in my view, are investment in alternative communication techniques and technology, formalised training in non-verbal communication, and a rigorous focus on supported decision making. The very definition of the term “communication” as prescribed under Article 2 of the Convention includes “augmentative and alternative modes, means and formats of communication, including accessible information and communication technology” (UN General Assembly, 2006, p. 4). Given that communication affects all the areas of a person’s life, it becomes imperative not only to provide appropriate communication methods and technology but also to train every person involved in the child’s life in using them. Such training should be targeted at people assessing their support needs, people helping them access those support needs, and people (from both formal and informal networks) actually delivering those support needs. The knowledge and expertise of the parents or other family members could be particularly helpful in both the design and delivery of training modules on non-verbal communication.

Finally, to uphold the rights of people with HCN to have a say in decisions affecting their lives, it becomes important that the policies of the service providers and the laws around guardianship promote supported decision making and not substitute decision making. Since the ratification of the UNCRPD by India and New Zealand, the rights activists of both countries have been calling for appropriate changes in the provisions concerning decision making in the National Trust Act 1999 and the PPPR Act 1988, respectively (McGregor, Bell, & Wilson, 2015; National Centre for Promotion of Employment for Disabled People, 2015; New Zealand Convention Coalition Monitoring Group, 2012). McGregor et al. (2015) argued that:

While much of the PPPR Act is consistent with the obligations under [Article 12 of] the Convention, it includes broad discretionary powers which allow the Family Court to grant Welfare Guardianship orders and make decisions on
behalf a person with some sort of disability. Such powers have the potential to be applied inconsistently with the Convention. (McGregor et al., 2015, p. 125)

Therefore, to fulfil their specific obligations under Article 12 and their general obligation under Article 4(1)(a) to adopt appropriate legislative and administrative measures, the governments of both countries must take urgent action in this regard to ensure that their legislation promotes truly supported decision making. The New Zealand Disability Action Plan 2014-2018 has also listed assisting disabled people in exercising their legal capacity through supported decision making as one of the actions that could assist in reducing barriers to disabled people making their own decisions (Office for Disability Issues, 2014). It, however, needs to be recognised that whilst people with HCN could be and should be supported as far as possible to make their own decisions particularly in relation to day-to-day activities, when it comes to certain decisions around consent for medical treatment or financial matters, some form of substitute decision making might be unavoidable. In such cases the decision maker/s must take all appropriate measure to ascertain the needs, preferences and best interests of the person. Further research might be helpful on how to make the concept of “supported decision making” work for people who are non-verbal and/or have limited cognitive ability to understand the implications of their decisions.

It needs to be noted that not many Delhi parents specifically talked about them and their children having a choice in the services they receive. One possible reason for that could be the very lack of services. For someone reliant upon formal support in India there would not be many options other than accepting what is on offer or going without it. Pinto and Sahur (2001) have provided another plausible explanation which is the influence of the cultural values. Referring to the lack of choice in health care they elucidated that:

> Indians respect the authority of the health care providers and feel their own role is passive. Consumers generally assume the role of the obedient recipient of services. In reviewing the literature, it becomes apparent that the traditional medical model in which the rehabilitation practitioner is the primary decision maker, with less emphasis on choice making by the client, is still the norm. (Pinto & Sahur, 2001, Section VII)
Based on the experiences shared by some of the Delhi parents of the nature of their interaction with the staff of the centres that their children attend, it could be safely argued that, even in non-health related disability support services, these families play the role of the obedient recipient of services that Pinto and Sahur refer to. However, as a signatory to the Convention, the government of India must monitor the operation of their new residential, respite and day care schemes to ensure that the people using those schemes are able to exercise choice and control over how they live their lives in those homes and centres.

**Address disability workforce issues**

The section on issues with formal support provided a detailed discussion on the various workforce related issues identified by the parents. The key issues were lack of appropriate knowledge and skills to work with people with HCN, shortage of staff, and high turnover; and according to the parents the factors responsible for these issues were lack of recognition of their work, low pay, lack of career path, and inadequate training opportunities. The parents suggested that, for their children to have a better quality of life, it was essential that the government took the necessary actions to resolve those issues as the support staff played a vital role in their children’s lives in all support areas.

In terms of the specific actions on the government part, some Auckland parents talked about more investment in the training of support workers with a specific focus on the specialist skills needed to support people with HCN and increasing the funding for the disability service providers so that they could pay better wages to, and training opportunities for, their staff. A need for providing better pay, working conditions and training to the disability support workforce has been raised time and again in the New Zealand literature (Beatson, 2004; Bray et al., 2005; New Zealand Disability Support Network, 2016; Social Services Committee, 2008). As emphasised in a recent report by the New Zealand Disability Support Network, “the days should be long gone when the

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8 It needs to be noted that, after the writing of this section, a new pay equity settlement has been announced that would take effect from 1 July 2017 and would substantially increase the pay rates of thousands of disability support workers across New Zealand (Ministry of Health, 2017). This is a very commendable step from the New Zealand government as it would not only assist to address the issue of lower pay scales but also might help resolve some of the associated issues mentioned in this section around high turnover and lack of career path as the proposed pay scales are linked with the workers' qualifications and experience in the sector. These changes would, however, be applicable primarily to staff employed by the service providers and unlikely to cover those employed directly by the families using individualised funding.
disability sector is competing with entry level jobs in supermarkets for direct service staff to undertake skilled and complex social service roles, however this is still the reality” (New Zealand Disability Support Network, 2016, p. 11).

In my personal experience of working in the New Zealand disability sector, due to the shortage of staff, the service providers often struggle to provide appropriate induction or on-the-job training to the new support workers in the form of giving them opportunities to do multiple shifts with the other experienced staff. The employees are sometimes even expected to start working alone (and unsupervised) with people with HCN with just one or two days of training from their supervisors or other senior staff. This puts both the disabled person and the support worker in a vulnerable position. Hence, it becomes vital that the funding provided to the service providers account for the extra costs associated with a thorough orientation and the training of the new employees, particularly when they are employed to support people with HCN.

With regard to formal training in the form of a recognised qualification in New Zealand, the review of the existing Careerforce and other relevant qualifications conducted by Te Pou identified certain gaps in relation to teaching the skills needed to provide adequate support to people with HCN and made certain recommendations (Te Pou o Te Whakaaro Nui, 2013). The government should work towards implementing the recommendations of the Te Pou report. Further, Te Pou acknowledged that their review did not include consultation with the families of people with HCN and hence it would also be helpful if the government conducted a further, similar, review of the qualifications in consultation with the parents.

Further, with the advent of the Enhanced Individualised Funding (EIF) initiative that provides funding directly to the service users as opposed to the service providers, the entire support industry is going through a big change with more and more disabled people and families being “employers.” Anecdotal evidence suggests that often the people employed by the families as caregivers are new to the support service industry with many employing people from their own informal network or fresh university graduates. Furthermore, the parents also prefer to train these people themselves in providing care to their children and hence they are unlikely to work towards a formal qualification in the sector. Over the last decade or so, the issues around pay scale, training needs and monitoring of this new breed of workforce employed directly by
disabled people and their family using individualised funding (or direct payments) has
got international attention (Scourfield, 2005; Shakespeare, 2014). Shakespeare (2014)
argued that lack of appropriate training to the personal assistants might make them
“vulnerable to harm” and lock them into “an unskilled sector of the labour market”
(Shakespeare, 2014, p. 179). Thus, the training capability of this workforce still remains
a major concern globally and with the MoH’s New Model of the disability support
services picking up pace in New Zealand, it has been suggested that training and
qualification of people employed directly by disabled people must be given due
c consideration (New Zealand Disability Support Network, 2016). In my view, the direct
payment packages should not only be adequate for the families to be able to offer a
decent wage to the people they employ but it should also include a specific “training
fund” component so that they could also provide the necessary training to their staff.

In the Indian context, there is an urgent need for creating an industry of trained disability
support workers to replace the care provided by untrained aayas. Whilst special
educators and other allied rehabilitation professionals would continue to play a
significant role in the disability sector, with the advent of the National Trust’s new
group home, respite care and day care schemes, a designated disability support
workforce is the need of the hour. Currently, the only relevant qualification for disability
support workers is the “Certificate Course in Care Giving” offered by the RCI
(Rehabilitation Council of India, 2017). This course must be reviewed to ensure that it
adequately covers the skills required to support people with HCN. A couple of Delhi key
informants also suggested that providing more disability related qualifications at tertiary
level could also help in attracting more knowledgeable professionals in the sector.

**Strengthen accountability and monitoring mechanisms**

Many parents of both groups had serious concerns around their children being
potentially subjected to physical, sexual, emotional or financial abuse and hence another
important change that parents wished for was an assurance that their children’s rights
and dignity would be safeguarded and protected. In this regard, the parents demanded
better safeguard measures in residential homes, day centres, and people’s individual
homes if they received home based support and improved monitoring of the trusts and
welfare guardians entrusted with the responsibility of managing property related or
financial affairs of people with HCN.
Given their additional concerns around their children not being able to report abuse or them not being considered a credible evidence if they report abuse, a couple of Auckland parents suggested conducting unannounced, random spot checks and installing CCTV cameras in residential homes and people’s individual homes as safeguard measures to prevent abuse. They mentioned that, if the government looked beyond the ethical concerns around people’s privacy, the surprise checks and the cameras could certainly be helpful in preventing abuse or providing additional evidence if it did happen. In relation to a lack of appropriate action on the part of the government to deal with the incidents of reported abuse, in their report on the review of the performance and quality management of disability support services, Van Eden, Grammer, and Russell (2013) asserted that:

It is unquestioningly the right of disabled people to call their accommodation ‘home’ and as such, to enjoy peaceful possession of it. But this should not be given as a reason for the Ministry [of Health] to hold back when it knows that something is wrong. The long-term wellbeing of the disabled is the paramount objective of DSS [disability support services]. (Van Eden et al., 2013, p. 40)

Thus, the government might need to weigh the privacy-related concerns against the protection-related concerns when it comes to contentious suggestions such as the use of CCTV cameras in people’s homes. It needs to be noted that during my field visits to disability organisations in Delhi I observed that using CCTV cameras for monitoring purposes was a common practice.

In the Indian context, as mentioned in Chapter 4, the organisations approved to run the National Trust’s group home, day care and respite care schemes are funded to provide free services only to 50% of the service users (who must be from BPL or LIG families), and are allowed to charge a fee to other families. In my view, a careful monitoring of the organisations running these schemes would be required to ensure that the children of paying families do not get preferential treatment over those from the LIG and BPL families.

Thus, the governments of both countries must take all the necessary measures as prescribed under various sub-articles of Article 16 of the Convention to prevent abuse from happening at all levels. As one Auckland mother emphasised, there should be zero tolerance for abuse:
I think that there is a lot of thinking in the industry that you know nothing is ever gonna be perfect in an ideal world, and you know all these default excuses for why problems exist and there is an acceptance that they will exist. Whereas, I am striving for none. That’s my bar – my bar is that there won’t be any abuse – there won’t be any of it. (Louise, Auckland parent)

**Improve administrative services**

Finally, the parents of both groups talked about a need for improvement in the administration of formal services. The Auckland parents talked about a need for reducing bureaucracy, better coordination between various government agencies, more flexibility in the use of allocated funding, a nodal agency acting as a one-stop shop that they could approach for their children’s support needs in all the areas, and reducing disparity between the funding provided by the MoH and the ACC.

Stop wasting time and money on unnecessary things like lots and lots of assessments for this and that. So many middle men in the system like you have got to go to the NASC agency if you want something or you got to have a referral from this and that and then it goes to a service provider who gets their cut of the funding. (Barbara, Auckland parent)

Make the system easier and user friendly so we don’t have to fight all the time.
(Donna, Auckland parent)

A need for better coordination across services that cover the full context of a person’s life was also identified in a United States based study involving families of people with intellectual disabilities (Hewitt et al., 2013). As mentioned in Chapter 4, the EGL concept currently being trialled in certain regions of New Zealand combines the funding from the three ministries and is designed to provide more integrated services across various aspects of a person’s life. Whilst this is a welcome initiative and a positive step in the direction of providing a better coordinated service, when applied to people with HCN, it would need significant adaptation to cover their specific “all of life” and “whole of life” support needs.

Regarding improving the administrative services in India, the suggestions of the Delhi parents, on the other hand, were significantly different given their own context of formal support. The Delhi parents talked about making administrative services such as the issuing of disability certificates and receiving free health care, hassle free, by providing
them at the local centres that their children attended and eradicating the menace of bribery and corruption – thus, their children could receive their entitlements without having to bribe government officials. A couple of Delhi key informants also talked about a need for reducing bureaucracy and reducing the corruption involved in the funding of various NGOs providing disability support services. Although not specifically mentioned by any of the Delhi participants of my study, a need for better coordination across various government agencies in India was identified in a publication entitled *Disability Development in India* by Singh and Dash (2014). They asserted that:

> Convergence is another worthy goal to be achieved for creating a bright future. Many Ministries, Departments and Institutions are working in this sector with their own agenda…. By working together all the agencies can make their task achievable within a definite time-frame and take the country towards the equalization of opportunities. (Singh & Dash, 2014, p. 162)

To conclude this section on the messages for the state, it needs to be acknowledged that, as suggested by numerous references to the literature and other studies in this chapter, many findings and the recommendations of this study also resonate in the works of other authors and researchers in India, New Zealand and internationally. For example, in the New Zealand context, many recommendations of this study align with the proposed actions under the Disability Action Plan 2014-18 (Office for Disability Issues, 2015), the outcomes prescribed under the NZDS 2016-2026 (Office for Disability Issues, 2016), and the principles of the EGL project (Enabling Good Lives, 2017). However, the discussion in this section has highlighted that some of the actions and outcomes proposed in these reports might need significant adaptation to meet the unique support needs of people with HCN.

As mentioned in the Findings chapter, many parents of both groups were extremely grateful to the government for whatever formal support they received. However, they also believed that their existing formal support would not be adequate to continue meeting their children’s and their families’ future support needs. They felt that, for them to be assured about their children’s quality of life after parents died, it would be crucial that the state took the necessary actions to implement the changes suggested above under various headings. However, as noted by Bray et al. (2005), “there appears to be a ‘culture of blame’ towards some carers who express their desperation for appropriate
support, and this is detrimental to meeting the needs of the family and the disabled child/young person” (p. 36). Hence, it is important that the parents are not judged or blamed for advocating for their children’s right to a good quality of life. After all, as Wendy pointed out:

It’s not about parents laying on a sob story – it’s our real lives. It’s not a sob story, it’s what we do. We are not complaining about it – we are just trying to get accurate support services to provide a healthy, fun, safe environment and it’s as simple as that. (Wendy, Auckland parent)

Before we move on to the next chapter, it is important to consider one other aspect in relation to the desired changes for the future. Under the section on desired supports, it was discussed that, whilst both formal support and informal support have their individual roles to play in disabled people’s lives, when it comes to supporting adults with HCN whose parents are not there, both systems need to work in coordination – one cannot do its job successfully without the support of the other. Similarly, from the discussion thus far in this section of desired changes, it has become evident that whilst both the state and the parents need to take certain actions to secure the future of adults with HCN, there are a number of areas where they need to work in partnership with each other to make those changes more effective. In other words, similar to a need for formal–informal interplay, there is also a need for the parent–state partnership when it comes to supporting people with HCN. A brief discussion now follows on the need for parent–state partnership and the form such partnership could take.

7.3.3 Parent–state partnership

First, it needs to be acknowledged that a need for the parents and the professionals/policy makers to work as partners is not a new concept and it has had prominence in the international disability literature over the last two decades (Brown, 1994; Endres & Kappel, 2015; Hewitt et al., 2013; James, 2013; Moore, 1992; Rehabilitation Council of India, 2014; L. Sullivan, 2005; M. Sullivan & O’Brien, 2005; Wills, 1994). This need has come from a growing recognition that, when it comes to young children with disabilities or adults with an intellectual disability, their parents are the experts on their needs and hence they must be consulted to provide adequate support to their children. As pointed out by Moore way back in 1992:
To understand a Parent’s perspective on housing and support for his or her adult son or daughter, it is vital to acknowledge the years of growing with that son or daughter. Feelings and history cannot be discounted. Unlike the professional who makes the decisions based on today’s realities and written records from the past, every Parent has a storehouse of vivid memories that influence all judgements. (Moore, 1992, p. 189)

The base of my argument for the need of parent–state partnership is also the same, namely that the parents are the true experts on the support needs of their adult children with HCN. As Lesley explicated:

A lot of the classical concern of course for us including a lot of parents is that, but we know him best, we have raised him, we know him the best, we care for him the best, we are deeply connected to him so we naturally have his best interest in mind. (Lesley, Auckland parent)

We have already identified that under various support situations, right from personal care to health care to social interactions, the parents are often called upon to interpret and communicate their children’s needs, pains, desires and preferences to others. The parents know what every single sign, gesture and grunting sound means; many other people would not know. As aptly explained by Joanna, they often develop a kind of a “secret code language” between them.

They express it by laughing or giggling or behaving manically and you can’t tell that they are in pain because they are not holding onto where it is paining and crying like you would expect them to. So it’s like they have all these [unusual ways of communication] and that communication is what I will have to train somebody so that they will recognise that something is wrong…. It’s like a secret code language. So if I can get someone to learn that secret code language, they will be the one who will have to decipher what’s going on. (Joanna, Auckland parent)

Therefore, it becomes critical that the knowledge that the parents have about their children’s care needs, medical condition, communication methods, and likes and dislikes is somehow captured and shared with as many other people as possible who are likely to be part of their children’s future lives. It is this capturing and sharing of parents’ knowledge where the parent–state partnership becomes crucial. Thus, what this study
has revealed is that when it comes to the future support of adults with HCN, the parent–state partnership is not just something *nice* to have but it becomes a necessity – something that *must* happen whilst the parents are still alive as otherwise there could potentially be a lot adverse consequences on the future lives of these children.

In the messages for the parents section, we identified a number of different actions that the parents need to take as part of their succession planning. It becomes crucial that the government provides appropriate support to the parents in all those areas so that the parents do not find that process overwhelming. Simultaneously, just as the parents need the support of the state to carry out their role, the state and the professionals must realise that they also *need* the support of the parents to carry out their role effectively because the parents as the users of the services know what works, what does not work and where the system breaks down. Therefore, they must consult with the parents on the matters affecting them and their children’s lives, not as a favour, but to adequately fulfil their obligation to provide the right support. A lack of consultation could not only lead to safety issues associated with poor quality care and inadequate services (Bray et al., 2005) but it could even amount to discrimination (New Zealand Convention Coalition Monitoring Group, 2015a).

I would argue that for the reasons discussed above, to provide adequate support to adults with HCN, the consultation with their parents should happen, not only at the needs assessment and service delivery levels, but even at the policy and research levels. In New Zealand, the acronym PPPR is used for the Protection of Personal and Property Rights (PPPR) Act 1988. I am hereby proposing a partnership model using the same acronym and I would like to call it: Parents as Partners in Policy and Research (PPPR) model.

*Parents as Partners in Policy and Research (PPPR) model*

The findings of this study have suggested that there is a real lack of understanding of the needs of the HCN population and this lack of understanding results in provision of services that often fail to adequately meet the support needs of this group. Therefore, parental input as the experts is needed right at the policy and research planning level to get the things right in the first place. Mere consultation at the service delivery level would be of not much help if the basic service design itself is faulty. As aptly put by an Auckland parent:
I think for too long the state has designed services for people without really checking that’s what people want and I think that has got to stop. (Mr J, Auckland parent)

Under the PPPR model, a partnership with the parents could be helpful in the following areas:

**Design of services**

The parents could provide expert advice to the policy makers and the service providers running group homes, respite care homes or day programmes on the design of both the physical layout of the premises as well as the planning of various activities that would suit the needs, the preferences and the pace of people with HCN.

**Design of funding models**

The parents could provide advice on adaptation of the service and funding models such as CCL, EIF and funded family care (in New Zealand) or the National Trust’s Gharaunda, Samarth, and Vikaas schemes (in India) to suit the specific requirements of the families of people with HCN.

**Drafting of policy and strategic documents**

The parental input becomes paramount in drafting of the national level policy documents such as strategies and action plans and bringing about disability related legislative changes. They could be helpful in ensuring that the plans and strategies do not weigh all disabled people using the same scale and that the unique needs of people with HCN are represented. The parents could also be the members of the advisory groups, co-design groups, or the committees responsible for drafting such documents.

**Evaluation and monitoring of services**

In addition to monitoring of the staff providing home based support, the expertise of the parents could be particularly helpful at the time of evaluation and auditing of the service providers for various certification purposes. The parents can also play an effective role in monitoring the implementation of CRPD and other national-level strategies at the ground level with particular focus on the rights of people with HCN.
**Workforce training**

The parents could play a vital role in upskilling of the workforce right from the review of the existing qualifications to designing new relevant training modules to actually delivering them on the ground. The service providers could also use parents’ help during the induction and orientation of the new staff particularly in relation to supporting people with HCN.

**Non-verbal communication**

As discussed earlier, another major area where the parent help could be of particular importance is around training in non-verbal communication to all stakeholders including disability support workers, health professionals, needs assessors and other government officials. If we take the example of the Deaf community, the hearing people within that community use sign language not only to communicate with their own Deaf family members or friends but they also often expand their knowledge and become professional interpreters. Whilst it is acknowledged that, unlike a sign language which is commonly understood by all its users especially in a given country, the tools and techniques used for communication by non-verbal people might vary significantly; nevertheless, the knowledge and the expertise of the parents or other family members of people with HCN could potentially be used in a professional capacity as non-verbal communication specialists. In other words, just as Deaf people have access to sign language interpreters to communicate with hearing people, non-verbal people should have access to “non-verbal communication specialists” to communicate with people who generally use verbal communication.

**Community awareness campaigns**

The parents could be the active partners of the policy makers in design and delivery of various community awareness programmes to bring about attitudinal change in the society.

**Research and development**

In the area of research, the parents could help in identifying the service gaps and highlighting the areas that need studying; working as co-researchers on certain topics; working as reviewers or moderators; or simply helping in recruitment of the other families for research.
The PPPR model aligns well with the findings of this study as the areas of partnership proposed above could help address a number of issues identified by the parents as well as in implementing the changes that they feel are necessary for the future. For example, creating service options that meet the age and impairment related needs of the people with HCN; designing qualifications that include specialist skills required to assist people with HCN; training of health and disability professionals in non-verbal communication; and so on.

The above list is not exhaustive, and there could be various other ways in which such partnership could work. Also, whilst the parents could provide their time voluntarily for some of the above activities, for many other things the parents could and should be provided appropriate monetary compensation for their time and expertise. Finally, given the discussion in the introductory chapter around these parents not having time or energy to attend various consumer consultation forums, some innovative solutions would be required for such a partnership model to work. First, to get better parental input, assistance of the parent support groups established specifically for the parents and/or carers of people with HCN (such as the Complex Carer Group in New Zealand) could be particularly helpful. Active parent members of such support groups could better represent the voice of the other parents in similar situation. The partnership with such groups could be informal, or be formalised to receive their support in the above areas. The views of the individual parents could also be obtained by providing them temporary daytime respite, where feasible, so that they could come and attend the meetings or fill out surveys. In India, conducting the consultation meetings at the centres that their children attend could help in reaching the parents who might not be part of any formal parent support groups.

Ferguson and O’Brien (2005) argued that one of the necessary change components for the disability professionals to move from “giving service” to “being of service” is to change their role from “agents of control” to “allies of emancipation.” I believe that a true partnership with the parents along the lines of the proposed model could certainly help the disability professionals, the service providers, and the policy makers to be the parents’ and disabled people’s allies in emancipation.
7.3.4 Desired changes – concluding remarks

In this section I discussed the specific roles of the parents and the state in securing the future of the adults with HCN beyond their parents’ lifetimes. It was emphasised that the parents cannot afford to leave certain decisions around their children’s future to chance and they must do timely succession planning to put appropriate things in place for their children. Similarly, we also discussed the parents’ suggestions on a number of actions that the governments of both countries would need to take to improve the services available to adults with HCN. Finally, highlighting the need for a strong partnership between the parents and the state in supporting each other to carry out their roles effectively, a different model for the parent–state partnership was proposed.

Whilst the recommendations in this section have global implications, they also include certain specific implications for policy and practice for both New Zealand and India under various headings. The discussion in this section has also highlighted a number of implications for further research which are now summarised below.

Implications for further research

The implications for further research are discussed in relation to: a) improving the understanding of the support needs of the families; and b) improving the design and delivery of services to better meet the support needs of the people with HCN and their families.

Support needs of the families

Further research in the following areas could be helpful in better understanding the support needs of the people with HCN and their families:

- Understanding the wishes, worries and the support needs of people with HCN themselves using appropriate non-verbal communication methods
- Understanding the views of the siblings of children with HCN on their roles in the lives of their disabled siblings after their parents and their corresponding support needs in carrying out those roles
- Influence of parental expectations from their children with HCN (in terms of their abilities) on the parental expectations for their children (in terms of services and quality of life)
• Influence of the family’s socio-economic background on the wishes of the parents living in developing and developed countries concerning their children’s long-term future and quality of life
• Understanding the wishes, worries and the support needs of the parents of people with HCN living in rural areas

**Design and delivery of support services**

Further research in the following areas could be helpful in designing better services for people with HCN and their families:

• designing innovative tools, resources, and devices to facilitate non-verbal communication with people with HCN;
• understanding the views of the parents (living in both the developing and the developed countries) on vocational occupation of their children without or with limited financial remuneration;
• experiences of the health professionals in supporting adults with HCN and their relevant training/support needs;
• understanding the parents’ and the support workers’ views on having CCTV cameras in residential homes and day centres;
• The impact of the welfare state on the families’ personal responsibility towards supporting disabled members of their family; and
• The impact of the welfare state on community responsibility towards supporting disabled or other vulnerable members of the society.

The suggestions above related to further research would help shed better light on some of the issues that were raised in this study but could not be explored in depth due to the study’s limited scope. The concluding section to follow summarises some very broad features and findings in this study that, in my view, have helped make a unique contribution towards exploring the answers to the nagging question at the top of the mind of every parent of an adult with HCN: What would happen to my child when I am no longer alive?

### 7.4 Conclusion

Linking the discussion in this chapter back to the triangulation of rights, choice and supports, all three broad sections have established how these three elements interact with each other. The Desired future section established a link between rights and choice by
highlighting that the kind of future chosen by the parents for their children is what their children are rightfully entitled to. The Desired supports section explained that the link between supports and choice is sometimes weakened by a number of factors that prevent disabled people from having a choice in the support they need. And finally, by referring to the various articles of the UNCRPD, the section on Desired changes highlighted that, to fulfil their obligations under the Convention, the state parties must take certain actions to uphold disabled people’s right to adequate support. Similar to Figure 1, Figure 4 also visually portrays the triangulation of rights, choice and supports as highlighted by the three sections of this chapter.

It is now time to review whether this study managed to achieve what it set out to do in terms of answering the research questions and fulfilling the research aim. This study is unique for two reasons. First, this is the only study of its kind to have a specific futuristic focus on the support needs of the adults with HCN beyond their parents’ lifetimes. Whilst some studies have looked at the support needs of the carers of disabled adults, their primary population has been the adults with an intellectual or developmental disability and not adults with HCN (Broadbent, 2003; Crandall-Mills, 2014; Lindblad et al., 2007; Shaw et al., 2011; Taggart et al., 2012). Similarly, whilst there are some studies that have looked specifically at the support needs of children or adults with HCN, their focus has been on the existing support needs and not on their futuristic needs after their parents’ death (Bray et al., 2005; Kersten et al., 2001; Milner & Mirfin-Veitch, 2012; Redmond & Richardson, 2003; Tucker, 2004). Secondly, this is also the first study of its kind to have included participants from two countries with access to significantly different levels of support systems. It could be argued that, due to its unique focus, this study has not only been reasonably successful in achieving what it set out to do but, at the same time, has also made its own unique contribution in a number of different ways as highlighted below.

In addition to help answering the research question on the wishes and the worries of the parents concerning the long-term futures of their children, the section on Desired future provided a unique insight into the influence of availability of varied levels of formal versus informal support on their wishes and worries. It suggested that, whilst good formal support could help to move beyond the thoughts of meeting basic survival needs to hope for a future where a person could live a more fulfilling social life and exercise better choice and control; good informal support becomes essential for emotional well-
being and meeting the need for love and belongingness. It also revealed that the parents in developing countries are generally more accepting of their personal responsibility in securing their children’s future than those living in the developed world with well-established welfare support systems.

Figure 4.
*Triangulation of Rights, Choice and Support in Practice*

The discussion under the Desired supports section helped answer the second research question around the support mechanisms that the parents consider to be crucial for the future support of their children after their own death. It further helped us understand
that, whilst both formal and informal systems have their individual roles to play in the lives of disabled people, when it comes to supporting adults with HCN whose parents are not around, neither system can work without adequate support from the other and there is a need for strong interplay between the two systems.

Finally, the section on desired changes helped towards fulfilling the research aim of making robust recommendations by providing some useful messages for the parents as well as identifying various implications for policy, practice and research. First, it highlighted that the parents must be proactive and put certain things in place whilst they are still alive, as leaving things until a crisis point is reached could have dire consequences for their children. Secondly, it provided some useful recommendations to the policy makers around adequately meeting the unique support needs of people with HCN. Finally, this section argued that, for adults with HCN to be supported effectively, a partnership with their parents is not a desirable ideal but an essential obligation on the part of the state. Identifying a need for a different kind or partnership, this study proposed a new partnership model – PPQR model – where the parents could be effective partners of the state in policy and research.

**The final word**

I am not worried about the length of her life – it’s about the everyday [how] she lives it. And if she did pass away, that’s the silver-lining. She would never be vulnerable to state care. (Louise, Auckland parent)

Our child should die before us because at least he has gone in front of our eyes and we don’t have to worry about how he will live in [the] future. (Nita, Delhi parent)

This study has helped us understand that the reason why Louise, Nita and many other parents in their situation think about outliving their children is because the society and the system has failed to: a) support these parents in their role; and b) assure these parents that their children will be safe after their own death and will lead good-quality lives.

To put it in the words of Campbell (2009), a large part of the reason for our failure as a society is that “we all live in ‘a world where disability may be tolerated but in the final instance, is inherently negative’. We live in an Ableist Society” (p. 17). This would need
to change. As a society, we have collective responsibility to ensure that no parents find themselves in a situation where they consider outliving their children as a better option than facing a prospect of leaving their children under someone else’s care after they themselves die. This study has highlighted that the responsibility of providing the necessary assurance to the parents about the future safety of their children must be shared by all people including extended family, friends, wider community and the state. It is only then that we will be able to create a society where people are comfortable with the idea of having a disabled child.

I dream, I imagine a world where families are equally as prepared to have a disabled child as a non-disabled child…. To me, that’s what utopia would look like. (Mr K, Auckland key informant)

Whilst we have still not reached the state of utopia that Mr K referred to, we have come a long way in recognising the rights of disabled people as equal citizens and contributing members of the society in international treaty documents such as the UNCRPD. A significant positive movement has also been seen in the direction of realising those rights in the form of innovative service models. These efforts need to be acknowledged and celebrated. As a matter of fact, since the time I embarked upon this research journey way back in 2014, the governments of both India and New Zealand have made a number of commendable improvements in both policy and practice. In India, the National Trust has introduced various schemes to provide better support services to adults with multiple disabilities and the government of India has also enacted its ground-breaking Act, The Rights of Persons with Disabilities Act, 2016. Similarly, New Zealand has advanced various innovative schemes under the MoH's New Model, has introduced the revised NZDS 2016-2026, has signed the Optional Protocol of the UNCRPD, has started working with the disability community to co-design the transformation of the disability support system and most recently entered into a historic pay settlement agreement to increase the wage rate of disability support workers. However, as highlighted in the chapter on triangulation of rights, choice and supports the factors such as economic considerations, gatekeeping of the funds by the assessors and progressive realisation clause have a particularly negative impact when it comes to meeting the social and economic rights of people with HCN. Therefore, for the above positive measures of the respective governments to make any direct impact on the lives of people with HCN and their families living in India and New Zealand, various suggestions given by the
participants of this study would need to be given due consideration. The strength of these recommendations lie in the fact that they represent the voice of the parents with years and years of experience in raising a child with HCN and reflect their views on what is likely to work for their children now and in the future when they themselves are no longer alive.

This section is entitled “The final word,” which, given the context of this study, must go to a parent:

I think seriously you can judge a country by how well they treat their vulnerable – I really believe that. You treat them with respect, dignity, understanding, empathy. It’s pretty simple really. (Wendy, Auckland parent)
Appendices

Appendix 1 – Ethics Approval Letter

Office of the Vice-Chancellor
Finance, Ethics and Compliance

UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)
18-Nov-2014

MEMORANDUM TO:
Assoc Prof Christa Fouche
Counselling, HumServ & SocWrk

Re: Application for Ethics Approval (Our Ref. 013284): Approved

The Committee considered your application for ethics approval for your project entitled
When I am no longer alive: Understanding the wishes, the worries and the support needs of the parents of severely disabled adults.9

We are pleased to inform you that ethics approval is granted for a period of three years. The expiry date for this approval is 18-Nov-2017.

If the project changes significantly, you are required to submit a new application to UAHPEC for further consideration.

If you have obtained funding other than from UniServices, send a copy of this approval letter to the Research Office, at ro-awards@auckland.ac.nz. For UniServices contracts, send a copy of the approval letter to the Contract Manager, UniServices.

In order that an up-to-date record can be maintained, you are requested to notify UAHPEC once your project is completed.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals. If you wish to do so, please contact the UAHPEC Ethics Administrators at roethics@auckland.ac.nz in the first instance.

Please quote reference number: 013284 on all communication with the UAHPEC regarding this application.

(This is a computer generated letter. No signature required.)

UAHPEC Administrators
University of Auckland Human Participants Ethics Committee
c.c. Head of Department / School, Counselling, HumServ & SocWrk
Hemant Thakkar
Assoc Prof Michael O'Brien

____________________________________

9 Please note that on 19 January 2017, the approval for the change of title of the thesis was granted by the School of Graduate Committee
## Appendix 2 – Interview Schedule (Parents)

### Interview Schedule:

<table>
<thead>
<tr>
<th>Questions</th>
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<tbody>
<tr>
<td>1. Tell me about what wishes do you have for your child’s future when you are no longer there</td>
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<tr>
<td>2. What changes do you think might be needed in your current support networks to fulfil those wishes?</td>
</tr>
<tr>
<td>3. Talk to me about the worries you might have concerning your child’s future when you are no longer there</td>
</tr>
<tr>
<td>4. What changes to your current support networks would help in reducing your worries?</td>
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<tr>
<td>5. What are your views on the significance of informal supports for severely disabled children whose parents are not there?</td>
</tr>
<tr>
<td>6. What are your views on the significance of formal supports for severely disabled children whose parents are not there?</td>
</tr>
</tbody>
</table>
| 7. How disability or disabled people in general are viewed in the community that you belong to (including by the State)?  
  a) What impact this might have on your child receiving the supports that you feel are necessary for his or her long-term wellbeing? |
| 8. **Tell me about the three most important:**  
  a) changes you would like to see happen for your child that would help you die peacefully  
  b) people in your child’s life besides you  
  c) suggestions you would like to give to the policy makers/ funders  
  d) suggestions you would like to give to the parents of other severely disabled people |
| 9. Is there anything else you would like to say or share? |
| 10. Do you have any questions for me? |
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