When I am no longer alive

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

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Summary

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1. Introduction

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. The issues faced by parents in raising a disabled child as reported in the literature include:

- difficulties in managing work–life balance;
- feelings 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; and
- worries about what would happen to their child if something happened to them.

Thus, the question, "*What will happen to my child when I am no longer alive?*", often troubles many parents of disabled children. However, for a majority of the ageing parents of adult children with high and complex needs (HCN), 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 attributable to the nature of the support they require (including intimate personal care), in association with deficits in cognitive and communication abilities hindering them in speaking up and fighting 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.

Each person with HCN is unique and can function well if his or her unique needs are met in certain ways. Those *certain ways of doing things* become second nature for parents by the time the child becomes an adult and hence they prefer to get involved (or are *expected* to be involved) even in various service-related decisions. Thus, in most cases, the parents of children with HCN end up assuming multiple roles in their children's lives including being their carers and/or advocates. However, playing such multiple roles not only takes its toll on the mental and physical health of the parents but just managing their everyday lives becomes a juggling act.

Maintaining resilience in the face of such 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 were to happen to the parents; and facing the

prospect of leaving their children under someone else's care becomes a matter of great concern.

The level of concern felt by the individual parents, however, depends upon their perception of how well their children would 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 (publicly funded) support and informal support (provided voluntarily by family, friends and others). 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, there has been an increasing demand from various disability groups across the world for greater choice and control over the decisions affecting their lives. Their efforts finally 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 Persons with Disabilities (UNCRPD or the Convention) that came into force in 2007.

The changes at practice and policy level in most Western countries (including New Zealand) included a gradual shift in the approach to supporting people using "independent living" models. Under the independent living models, funding is often given directly to a disabled person (or his or her agent) as opposed to a disability service provider. 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, the global literature suggests that, at a practice level, for a myriad of reasons, the funding-related decisions are primarily driven by economic considerations and disabled people seldom get any real choice.

In a developing country like India, 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, 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 meet their care and support needs.

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 situations in these two countries also highlight the pressure that policy makers of both developing and 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 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. Policy makers can gain such real understandings by consulting with the people whose lives will be affected before making crucial policy decisions. However, 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 and, as a result, the voice of people with HCN and their families is often not heard.

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. Overview of Research Methodology

The primary aim of this study was 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 catering for the specific support needs of adults with HCN and their families.

With the above aim in mind, the following two key research questions were 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?

Given the sensitive nature of the topic, a qualitative methodological approach was considered appropriate for this study. Using purposive sampling, 14 parents from Auckland, New Zealand and 18 parents from Delhi, India were selected as the participants for this study.

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. A total of 13 key informants were interviewed – six in Auckland and seven in Delhi. All the participants were provided with a Participant Information Sheet (PIS) and an Informed Consent (IC) form approved by the University of Auckland Human Participants Ethics Committee (UAHPEC). Personal interviews were conducted with all the participants using a semi-structured interview schedule. All the interviews were audio recorded and transcribed by the researcher. Finally, thematic analysis of the transcripts was conducted using NVivo™, a form of qualitative data analysis software, to generate meaning from the data.

2. Key findings and recommendations

Preamble: This section includes a summary of the key findings as presented in the 'Discussion and conclusion' chapter of the main thesis; however, I would strongly urge that readers refer to the 'Findings' chapter of the thesis to get a more vivid account of the participants' voice as this includes invaluable direct quotes from the parents as well as the key informants. Also, whilst the discussion in the thesis is supported by a number of references from the literature and other research studies, to maintain the brevity of this document, this section summarises the key findings primarily from the participants' perspectives.

The first research question of this study 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 part is presented under the three broad sections entitled "Desired future", "Desired supports" and "Desired changes".
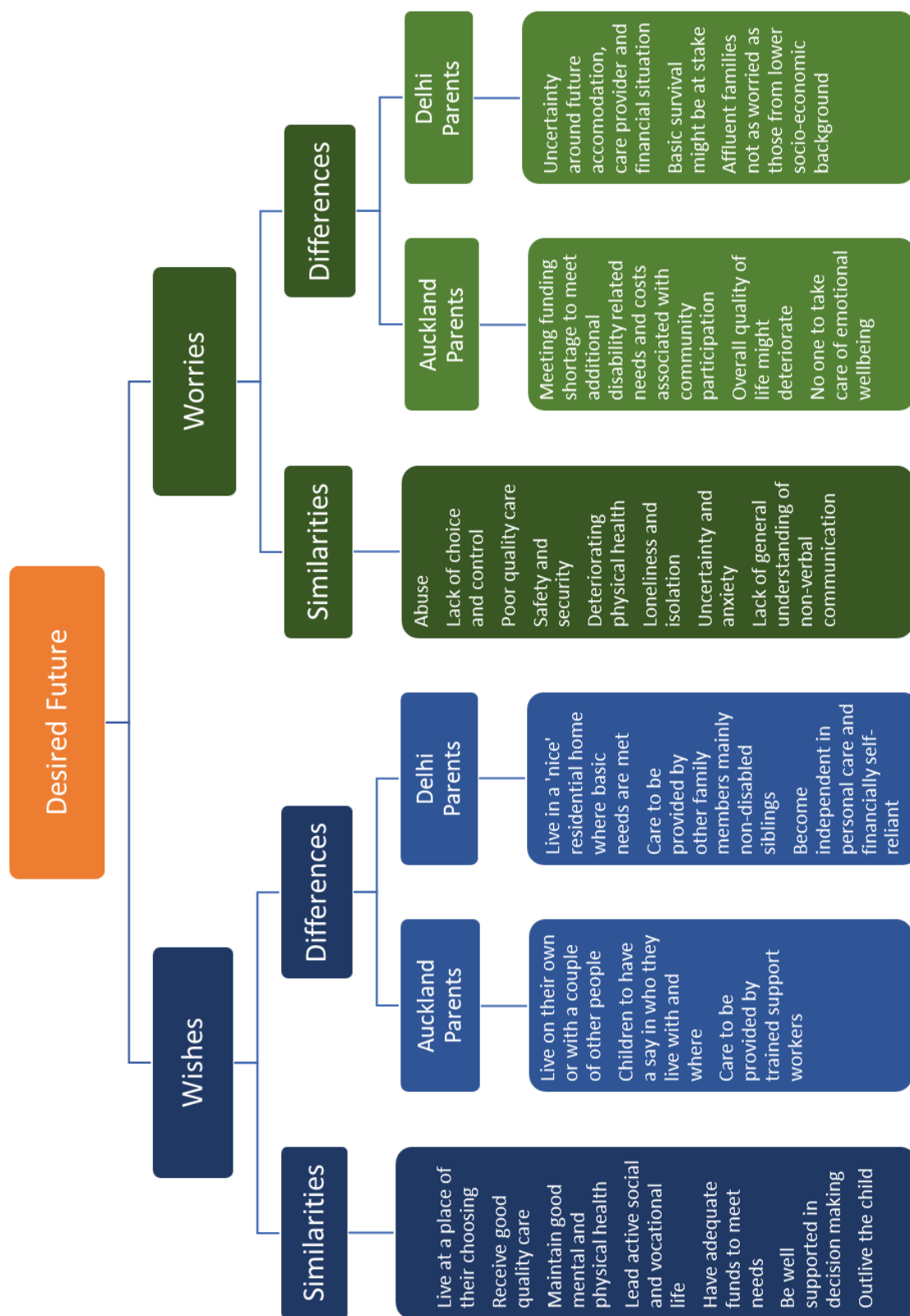
2.1. Desired future

This section discusses the type of future that the parent participants envisioned for their adult children with HCN beyond their own lifespan and summarises the study findings concerning the wishes and worries of the parents.

A review of the existing support system of the participants suggested 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, whilst there were common themes in the wishes and worries of the parents of both groups, within those broad themes there were differences in the specific wishes and the worries which could be attributed to the differences in the availability of formal and informal support to both groups of parents. Figure 1 summarises the similarities and differences in the wishes and worries expressed by both groups of parents.

In a nutshell, 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 an Auckland parent. Whilst a majority of the Delhi parents (given the lack of formal support), were preoccupied with thoughts of meeting their children's basic survival needs after parents have died, the Auckland parents had taken basic survival for granted and were worried that, without appropriate additional support, their children might just survive but not be able to "live" their lives. 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 as other citizens do or be denied opportunities to exercise any choice and control over how they live their lives. It needs to be emphasised, however, that those Delhi parents who were in a financial position to take personal responsibility for the future well-being of their loved ones or those who had good informal support from their other family members could still realistically wish for a good quality of life for their children despite a lack of formal support.

Figure 1. *Summary of Findings: Desired Future*

Desired Future

Worries

Differences

Delhi Parents
- Uncertainty around future accomodation, care provider and financial situation
- Basic survival might be at stake
- Affluent families not as worried as those from lower socio-economic background

Auckland Parents
- Meeting funding shortage to meet additional disability related needs and costs associated with community participation
- Overall quality of life might deteriorate
- No one to take care of emotional wellbeing

Similarities
- Abuse
- Lack of choice and control
- Poor quality care
- Safety and security
- Deteriorating physical health
- Loneliness and isolation
- Uncertainty and anxiety
- Lack of general understanding of non-verbal communication

Wishes

Differences

Delhi Parents
- Live in a 'nice' residential home where basic needs are met
- Care to be provided by other family members mainly non-disabled siblings
- Become independent in personal care and financially self-reliant

Auckland Parents
- Live on their own or with a couple of other people
- Children to have a say in who they live with and where
- Care to be provided by trained support workers

Similarities
- Live at a place of their choosing
- Receive good quality care
- Maintain good mental and physical health
- Lead active social and vocational life
- Have adequate funds to meet needs
- Be well supported in decision making
- Outlive the child

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 (which both New Zealand and India are signatory to). Similarly, the Convention also provides for specific protection against some of the worries expressed by the parents.

So the fact that, despite having the protections afforded under the terms 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; and are failing to provide the necessary assurance to these parents concerning their children's long-term well-being.

2.2. Desired supports

This section discusses the support necessary to convert the parents' vision of the desired future into a lived reality for their children. It highlights the parents' views on the role that both formal and informal support could play in having their wishes concerning their children's future come true; and it also explores the link between the parents' worries as discussed in the previous section and the issues/challenges with accessing both formal and informal support. Figure 2 summarises the key similarities and differences in the views of both groups of parents on the significance of, and the issues with, formal and informal 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 also influenced their expectations of the role that the formal support system should, and could, play in various aspects of their children's future. For example, 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 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.

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. For example, when discussing disability workforce related issues, Auckland parents talked about 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; Delhi parents, on the other hand, highlighted the complete absence of a designated disability support workforce. In residential homes, care plans and day programmes are often prepared by the special educators and personal care is 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 for their children even if they were willing to pay. Delhi parents also highlighted some additional issues with formal support around bribery and corruption and inaccessible health care and disability administrative services.

In summary, the participants of both countries felt that formal support was extremely significant in order for their children to live good quality lives. 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.

Significance of informal support

As mentioned in the introductory section, 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 suggests 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. 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 no longer around.
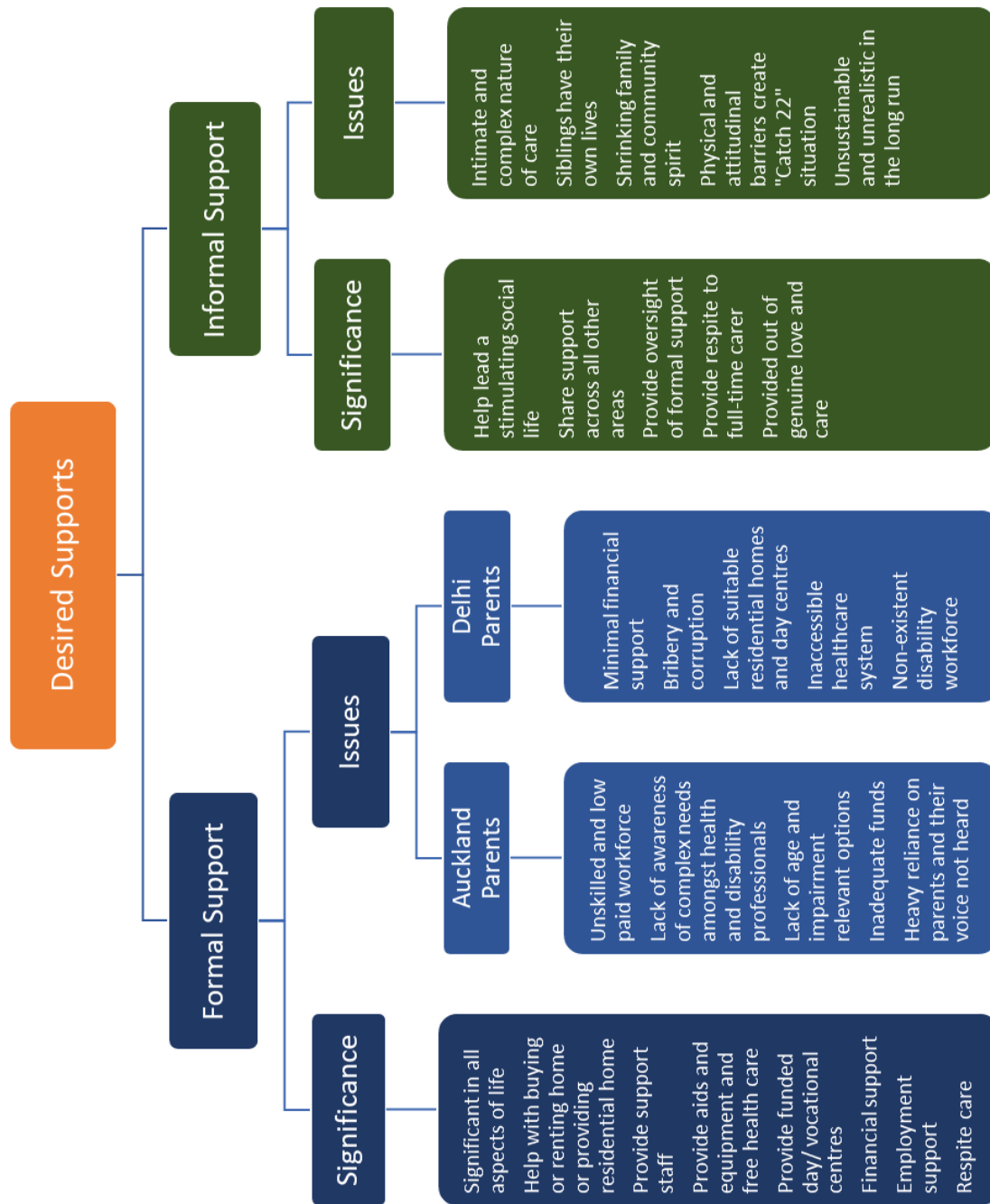
Finally, many parents (and the key informants) felt that, in certain areas, such as emotional support and friendship, informal support could be more significant than formal support as it is often provided by people acting out of genuine care, concern and love for the person as opposed to it just being a job.

Issues and challenges with informal support

Whilst the key issues raised by both group of parents in relation to informal support are listed in Figure 2, a few points require specific mention. First is the issue surrounding the intimate and complex nature of care. The parents of both groups felt that, when it comes to personal care or health-related needs, the level of care required by their children is too intimate and/or complex to expect people from the informal network to provide it. The second major issue with informal support is around shrinking family size and less community spirit. Many parents (of both groups) were of the view that people had become more self-oriented and the community spirit of earlier days was lacking in modern society resulting in less access to informal support. 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 both nuclear and physically distant. Finally, a number of parents talked about the negative impact of community attitudes and beliefs concerning acceptance of disability. For example, in India many disabled people and their families face social exclusion due to the Hindu philosophy of karma with disability being seen as a result of the sins of past lives.

In addition, 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 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.

Figure 2. *Summary of Findings: Desired Supports*

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Desired Supports

Formal Support

Significance
- Significant in all aspects of life
- Help with buying or renting home or providing residential home
- Provide support staff
- Provide aids and equipment and free health care
- Provide funded day/vocational centres
- Financial support
- Employment support
- Respite care

Issues

Auckland Parents
- Unskilled and low paid workforce
- Lack of awareness of complex needs amongst health and disability professionals
- Lack of age and impairment relevant options
- Inadequate funds
- Heavy reliance on parents and their voice not heard

Delhi Parents
- Minimal financial support
- Bribery and corruption
- Lack of suitable residential homes and day centres
- Inaccessible healthcare system
- Non-existent disability workforce

Informal Support

Significance
- Help lead a stimulating social life
- Share support across all other areas
- Provide oversight of formal support
- Provide respite to full-time carer
- Provided out of genuine love and care

Issues
- Intimate and complex nature of care
- Siblings have their own lives
- Shrinking family and community spirit
- Physical and attitudinal barriers create "Catch 22" situation
- Unsustainable and unrealistic in the long run

In summary, the findings of this study suggest that, to adequately meet the social and economic rights of people with HCN as prescribed under the Convention, 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 study further highlights a very important element concerning the interplay between formal and informal support systems. It reveals that, when it comes to supporting adults with HCN whose parents are no longer alive, one system cannot deliver even the desired outcomes successfully in certain areas without the support of the other system. For example, due to the nature of their impairment, if people with HCN do not have reliable people in their informal network to advocate for them they might struggle to even access appropriate formal support. Similarly, 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 medical expenses.

Thus, 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.

2.3. Desired changes

This section primarily focuses on the research aim of making useful recommendations for design and delivery of disability services that could cater for the specific support needs of adults with HCN and their families. Primarily, 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".

Key messages for the parents

In addition to talking about what they would do for their own children, the parents also provided some useful suggestions for other parents in a similar situation to theirs around succession planning. Key messages from the participants of my study included:

- **Preparing the children** to live without them by training them in looking after their own home and personal care needs; and increasing the frequency of sending their children to respite care with a view to gradually getting them used to the idea of not having the parents around 24x7.

- **Preparing the informal network** of family and friends in supporting their children after their death. This included identifying potential successor/s; appointing welfare guardian/s; creating a circle of support; and providing training to all concerned around their children's support and communication needs.

- **Sorting out the living arrangements** by either checking out the suitability of the available residential options for their children or buying or renting a house, or transferring their house to their disabled child's name or into joint names with their other, non-disabled, children.

- **Securing the financial future** of the children by preparing a will, putting some funds in the child's name, getting assurance from other family members about 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.

- **Creating a life plan and a training manual** detailing their children's support needs, likes and dislikes, and goals and aspirations. The training manual could providing minute details of how to meet their children's health and personal care needs and may include instructions in audio-visual formats.

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. This section summarises the parents' suggestions 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. It should be noted that, whilst this section discusses some specific implications for India and New Zealand, overall, it has global implications for policy, practice and research.

- **Change attitudes:** The parents as well as the key informants 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 policy makers and politicians. Key suggestions for the state in this regard included changing the mentality from a "welfare" approach to one of an "investment" approach; and 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:** The government must recognise the additional support needs of adults with high and complex needs when making funding- and service-related decisions in all areas including residential services, health care, day/vocational services, and financial support.

- **Provide the necessary support to the successor/s:** Many Auckland parents 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.

- **Work towards exploring alternative sources of support:** Recognising the constraints on state resources, one Auckland parent talked about the significance of support of the student volunteers; some Delhi parents and key informants talked about the roles of voluntary organisations (NGOs) and the private sector (through their Corporate Social Responsibility – CSR schemes) in complementing the formal system in supporting their children.

- **Address disability workforce issues:** Auckland parents suggested more investment in the training of support workers with a specific focus on the specialist skills needed to support people with HCN; and higher wages and better career paths for support workers. In the Indian context, an urgent need for creating an industry of trained disability support workers was identified to replace the care provided by untrained maids (*aayas*).

- **Enable choice and control:** 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; including them and their children in all decisions affecting their lives; and making appropriate legislative changes to promote true supported decision making.

In addition to the above suggestions, the participants also identified a need for the governments to work towards removing physical and attitudinal barriers from the community; strengthening accountability and monitoring mechanisms; and improving administrative services.

This study has highlighted one other, crucial, 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, it became 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 parent–state partnerships when it comes to supporting people with HCN. A brief discussion now follows on the need for parent–state partnerships and the form such partnerships could take.

Parent–state partnership
There is 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. The parents know what every single sign, gesture and grunting sound means; many other people would not know. As one Auckland parent suggests, they often develop a kind of a "secret code language" between them. Therefore, it becomes critical that the knowledge that the parents have about their children's needs, preferences and communication methods is somehow captured and shared with as many other people as possible. It is this capturing and sharing of parents' knowledge where the parent–state partnership becomes crucial. Such partnership is not just something *nice* to have but something that *must* happen whilst the parents are still alive as otherwise there could potentially be a lot of adverse consequences for the future lives of these children.

I would argue that, for the reasons discussed earlier, to provide adequate state support to adults with HCN, consultation with their parents should happen, not only at the needs assessment and service delivery levels, but even at fundamental policy and research levels. Therefore, this study proposes a unique partnership approach called the Parents as Partners in Policy and Research (PPPR) model.

Parents as Partners in Policy and Research (PPPR) model

This model is founded on the premise that, when it comes to supporting adults with HCN, expert parental input is needed right at the basic policy and research planning level – to get things right in the first place. Mere consultation at the service delivery level will not be of much help if the basic service design itself is faulty. Under the PPPR model, a partnership with the parents could be helpful in the following areas:

- Design and delivery of services
- Design of funding models
- Drafting of policy and strategic documents
- Evaluation and monitoring of services
- Workforce training
- Non-verbal communication
- Community awareness campaigns
- Research and development

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. 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. Assistance from 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 also be particularly helpful in accessing parental input.

3. The final word

I am not worried about the length of her life – it's about the everyday [and 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 reasons why Louise, Nita and many other parents in their situation think about outliving their children is because society and the system have 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. 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 the prospect of leaving their children under someone else's care after they themselves die.

It needs to be acknowledged, however, that 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. 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 including increased investment in the sector and efforts to transform legislation as well as service delivery systems. However, 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, the various suggestions made by the participants of this study would need to be given due consideration. The strength of these recommendations lies in the fact that they represent the voice of the parents with years and years of experience in raising a child with HCN.

This section is entitled "The final word" which, given the context of this study, must come from 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)