Parental engagement in caring for and educating children with disabilities in a western region of Nepal: Experiences and perspectives of parents and professionals

by

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Dedication

To my late father **Humlal Pokhrel**

and

mother **Mina Kumari Pokhrel**

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Summary

The aim of this research was primarily to elicit the experiences and insights of parents of children with disabilities in a western region of Nepal and, in addition, the perspectives of local teachers, head teachers, community members and government officials. A relational approach has deeply informed all facets of this qualitative research, from the way the researcher conducted informal interview conversations with the participants in their own language and in their own homes, local tea shops and schools, to the way vignettes for the focus group discussions were created to highlight the richness of parents' insights, joys and challenges as they raised their children. These research methods underpinned by a relational research approach provided participants with a safe and empowering environment in which to air issues. Similarly, case-focused portrayals and thematic narratives, drawing on the narrative approach to data presentation and interpretation, were able to draw out socio-cultural and institutional factors relating to the parental experiences and challenges of caring for and educating their children.

The key finding that emerged from this research is that Nepalese parents of children with disabilities are greatly invested in their children's education, and want to be involved and work in partnership with teachers, yet there are significant barriers preventing them from doing so. They are a significant untapped resource and, until this study, the extent of this commitment of parents to the education of their children was not known.

In addition, this research has found that parents feel confused and uncertain as their traditional folk wisdom about disability conflicts with the scientific knowledge they are increasingly encountering through their efforts to access different services and increasing media coverage in rural areas. The lack of external support for these families has further left them alone to live and deal with their children's disability. Moreover, women and girls of families living with children with disabilities are more affected than their male counterparts, due to women's stereotyped roles and the continuing dominant patriarchal culture in Nepal. Moreover, parents are deeply concerned about the healthcare needs of their children with disabilities, prior to the schooling of these children, suggesting that the health and education needs of their children with disabilities are intricately linked and hence the need for collaborative approaches to service delivery to help these families to meet their children's needs.

The focus of current interventions in Nepal is largely based on government-sanctioned scientific knowledge that tends to ignore folk wisdom and expertise. This has led parents to perceive themselves as incompetent, which has undervalued their existing strengths to contribute to modern processes. It is clear that greater care is needed to develop interventions to suit the local

circumstances, drawing on grassroots folk wisdom and contextual needs. It is hoped that the findings from this research will help policymakers and communities to create bridges between local and scientific knowledge, such as home and school, so that both parents and teachers can begin to feel more confident in working together for the wellbeing and learning of the children.

Declaration

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and

2. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Kamal Prasad Pokhrel (Sharma)

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The Beam

Elizabeth Mosely

Poem is available online from: http://wwda.org.au/poems/wwdapoems/poem3/

(Published on the webpage of Women With Disabilities Australia -WWDA, 164 Elizabeth St North Hobart TAS 7000, PO Box 407, Lenah Valley TAS 7008; Phone: 0438 535 123 Executive Director: Carolyn Frohmader, email: carolyn@wwda.org.au)

CHAPTER 1 - INTRODUCTION: SETTING THE SCENE

> It is in everyone's interests for parents to be welcomed and supported to work as allies with teachers, principals and others in the educational process. Parents can help teachers and principals strategize and build on their children's strengths. Policy should reflect that orientation and practices should support it. (Crawford, 2009, p. 57)

1.1 Introduction

Nepal is a country steeped in culture, history, ethnic diversity and political upheavals. It is famed for its natural beauty and geography including eight of the highest mountains on earth. However, it is also identified as one of the world's twenty poorest nations (World Bank, 2019). A landlocked country situated between China and India, it continues to be heavily reliant on international aid. Devastating earthquakes and floods in recent years have challenged the country's goals of reducing poverty rapidly and improving the quality of people's lives (National Planning Commission [NPC[1]], 2016). The low Human Capital Index locates Nepal as a nation with poor access to health services and educational opportunities, suggesting that young people's opportunities to move beyond their current familial circumstances will continue to be restricted (World Bank, 2019). With these contextual conditions in mind it is not surprising that marginalised groups such as children with disabilities[2] are not at the forefront of initiatives designed to improve the quality of life and economic benefits for Nepal's population. Yet, countries seeking to develop are wise to recognise the rights of all their citizens and the contributions that can be made by all.

In recent years, some positive changes have been observed in the fields of health and education in Nepal. For example, governments, both national and local, have acknowledged the benefit of early childhood education in developing over 35,000 Early Childhood Education and Development centres across Nepal (Dawadi, 2019) and now the vast majority of 4 to 5-year-old children in Nepal have access to early childhood education. However, young children living with disabilities have not been included in these education programs and there has been very little evidence of the parents of these children protesting about the exclusion of their children. This tends to suggest that parents of children living with disabilities in Nepal either accept their situation and/or have not had an opportunity to speak about their experiences of parenting children with disabilities or the aspirations they hold for their futures. In developing the scope of this research, I was unable to locate any research from Nepal on parent engagement or advocacy for their children living with disabilities seeking access to educational opportunities similar to other children in Nepal. And yet,

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[1] Please see Appendix A, Glossary (Part I) for the list of all acronyms used in this thesis.

[2] Please see Appendix A, Glossary (Part II) for definitions of the key terms in this thesis.

this is an area of significant development in western countries, where parent empowerment is prioritised by government policies, parents have legal rights to challenge any form of discrimination against their child by educational authorities, and parent–school partnerships are an expectation (Turnbull, Turbiville, & Turnbull, 2000; Turnbull, Turnbull, Wehmeyer, & Shogren, 2013; see also Byrne, 2001). Clearly, there are vastly different contextual conditions between Nepal and more developed countries in the understanding of parenting children living with disabilities. For example, in more developed countries improved outcomes for families of children living with disabilities have resulted from parents being advocates for their children and ensuring their voices are heard by those in positions to make a difference to policy and actions (Peters, 2004; de Boer, Pijl & Minnaert, 2010; Wong, Poon, Kaur, & Ng, 2015). From my own experience, shared shortly, I am acutely aware that many groups in Nepal are marginalised and their stories not considered in national and local government policy development and strategic planning. The parents of children living with disabilities are one such group and therefore the primary focus of this research is giving voice to these parents, and in doing so seeking to understand their experiences and how this can contribute to improved policy and actions by local and national governments to create more inclusive communities and opportunities for all.

The research was conducted in a western district of Nepal as this rural location included families of children living with disabilities who were even more marginalised than those living in urban areas. I directly sought out experiences and insights of parents of children with disabilities as well as of local professionals, community members and local government officials to determine similarities and differences in experiences and perceptions and how their stories could contribute to increased understanding for action.

In this introductory chapter, I provide a further rationale for my interest in the area of research, examining in more depth the background and context of special needs education in Nepal in relation to very limited parental engagement in the education of their children. I expand on the link between the contextual conditions and choice of methodology, and clarify the research questions, the significance of the research and structure of the thesis. Finally, I will present an *a priori* reflection on my prior knowledge, values and beliefs relevant to this research. This describes the impetus and my motivation for this research, and also provides insight into the disposition I bring to the research.

1.2 Background to the research

Nepal's enormous diversity is manifested in its languages, ethnicities, cultures, religions and geography. It is home to people who speak 123 languages from 92 different ethnic groups (Yadava, 2007). Geographically, the altitude ranges from the highest peak in the world – Mount Everest (8848 metres) – to land which is only 22 metres above sea level. Administratively and politically Nepal is divided into seven provinces, 77 districts, 6 metropolitan cities, 11 sub-metropolitan cities, 276 municipalities and 460 rural municipalities (known as *gaunpalikas*) (Acharya, 2018). More than 80% of Nepal's population live off subsistence-based agriculture (Food and Agriculture Organisation [FAO], 2015). A remittance-based economy prevails with a large number of youths going to South-East Asian and Gulf countries in search of work. While 86% of the population is rural-based, only 14% of people live in the cities. Despite being only 0.1 per cent of the total world's area (and 0.3% of Asia), Nepal possesses almost 3, 4.5, 5 and 9 per cent of the world's species of flowers, mammals, bryophytes and birds, respectively (Ministry of Forests and Soil Conservation [MFSC], 2014), making the nation one of the richest biodiversities on earth. While the majority of Nepalese are Hindu (80%), the rest of the population follow Buddhism (10%), Islam (4%), Christianity (1%), Jainism, Sikhism and other religions (MFSC, 2014).

Broadening access to education for its children has been a priority in Nepal for many years. Nepal is committed to providing education to all children as it is a signatory of various United Nation (UN) conventions[3] and international agreements such as the Jomptien, Salamanca, Dakar and Incheon agreements related to children's right to education (Barriga, 2011; National Human Rights Commission [NHRC], 2009; UNESCO, 1990, 1994, 2000, 2015). However, the objective of Education for All (EFA), which is to have every single child in school, is not yet fully realised (Centre for Educational Research Innovation and Development [CERID], 2008; Dhungana, 2014). A recent official document (Department of Education [DoE], 2017) reveals that the net enrolment rate of basic school age children (5–12 years) is 92%. Although Nepal has made tremendous progress towards universal enrolment, unfortunately, the majority of those who are excluded from the education system now are children with disabilities (Centre for Education and Human Resource Development [CEHRD], 2018; Dhungana, 2014).

The lack of comprehensive and rigorous databases for the disability population has also been an issue in Nepal. Data regarding the prevalence of disability varies from 2 per cent, according to government sources (Central Bureau of Statistics [CBS], 2012), which is perceived as a conservative figure, to more than 25 per cent (according to the Social Science Research Foundation, cited in Barriga, 2011, p. 14), which is considered an inflated figure. However, the World Health Organization's (WHO) estimation of about 10 per cent prevalence in Nepal (that is, 2.8 million of a

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[3] Universal Declaration of Human Rights (UDHR) 1948, UNESCO Convention against Discrimination in Education 1960, UN International Covenant on Educational, Social and Cultural Rights (ICESCR) 1966, UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) 1979, UN Convention on the Rights of Child (CRC) 1989, UN Convention on the Rights of Persons with Disabilities (CRPD) 2006.

total population of 28 million) serves as a more agreed figure (Barriga, 2011; Dhungana, 2014; WHO, 2011). The data from the 2011 Census in Nepal further infers that about 1.2 million children under 18 years of age have a disability (CBS, 2012; WHO, 2011).

It is argued both internationally and in the local context that any country and society cannot simply ignore the needs and rights of people with disabilities, as no society can move forward without advancing all its people (Secretariat of Constitution Assembly [SCA], 2015; UNESCO, 2015). Inclusion is an issue of great significance in the current debate, especially in this post-modern era, even for developing countries, and even more so for Nepal because of its diversity and presence of discrimination in terms of gender, religion, culture, caste, class, geography, ability and language (Brandt, 2015). In Nepal, the provisions made through different legislatures, including the newly ratified constitution, suggest that it is keen to be an inclusive society (SCA, 2015). However, achieving inclusion is not straightforward in developing countries when resources are limited, priorities are divided, and cultural beliefs tend to discriminate against people with disabilities and their families. Education, however, is considered a powerful vehicle to achieve inclusion, as it is believed that education equips people with knowledge, skills, confidence and informed attitudes and orients people towards transformation (Hammad & Singal, 2014, 2015). In this respect, Nepal also needs appropriate provision of quality education for all children including the disadvantaged and those living with disabilities.

In Nepal, three key approaches to education targeted for children with disabilities are in practice: special, integrated and inclusive education (CEHRD, 2018; Kafle, 2002; Plan, 2014). While special education offers specialised instruction to children with disabilities in a separate school; integrated education provides instruction in a separate classroom but within a mainstream school's premises, in most cases with provision of a residential facility (CEHRD, 2018). Similarly, inclusive schools are designed to educate all children (with or without disabilities) together in the same class. There are currently 34 special and 380 integrated schools in Nepal; however, there is limited evidence of inclusive schools in practice (CEHRD, 2018; DoE, 2017). Although these different types of educational provision targeted to children with disabilities carry different meanings or philosophies about disability and interventions, it is worth mentioning here that the term 'inclusive education' is sometimes used in Nepal to refer to any of these types of education provision. Barriga (2011) asserts that in Nepal 'the meaning of inclusive, integrated and special education is often not well understood' (p. 28). In this research, I use the term 'special needs education' to refer to all types of education provision that are targeted to children with disabilities. This use of the term is in line with

Clark, Dyson and Millward's (2005, p. 6) use of 'special schools' to refer in general to all three types of schools.

The Government of Nepal (GoN) conceptualises inclusive education as a tool to bring not only children with disabilities but all types of disadvantaged children into mainstream schools, including *Dalits*,[4] marginalised groups, street children, ethnic and language minorities, the socio-culturally oppressed, trafficked children, bonded child labour, children with emotional difficulties, girls, conflict-affected children, orphans and remote area dwellers (CERID, 2004). As articulated by Rose (2018b), this policy of Nepal is comparable with Indian educational policies, which attempt to be both 'inclusive and equitable' in inviting disadvantaged children into schools, as 'the impact of caste, poverty, gender and disability has remained pervasive' and prevents a massive number of children from accessing education (p. 1). However, this research focuses on the inclusion of children living with any type of disability including physical, sensory (visual, hearing), intellectual and autism as some primary examples. Nevertheless, in this research I plan to adequately discuss other associated aspects of disability that interact with various other situations, such as caste, poverty, gender and other sociocultural factors (Rose, 2018b), with an acknowledgement that disability is a 'heterogenous and multidimensional concept' (Hammad & Singal, 2009).

Studies in Nepal suggest that one-third of children with disabilities continue to be deprived of educational services (Acharya, 2007). The Department of Education (DoE) reports that approximately 77000 students with disabilities are in schools from pre-primary to higher secondary level (CEHRD, 2018; DoE, 2017), although these data in general are not consistent in Nepal (Barriga, 2011). While studies reveal that many children with disabilities are left out of the school system, many of those who are already enrolled in schools also do not receive quality education (Acharya, 2007; Regmi, 2017). Several factors have been reported to contribute to this, including long distance to school from home, lack of information, negative attitudes towards education, lack of support for families and their low incomes, inadequate facilities, teachers' incompetency, lack of specialist resources and the need to adapt the curriculum (Acharya, 2007; Oosterlee, 2012; Plan, 2014).

The experiences, voices and concerns of parents or families of children with disabilities, and of local communities about disability, are equally important resources for the fuller understanding of issues surrounding special needs education (Beveridge, 2005; Bhattachan, 2005; UNESCO, 2009a). Sharma, Loreman and Macanawai (2016), following research in the South Pacific, indicate: 'It is important

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[4] *Dalits* are a so-called lower caste group in the traditional caste-based hierarchy. Discrimination against *Dalits* was common in India and Nepal and still exists in some form or other, although it is legally banned. Please see Appendix A, Glossary (Part III) for the list of key Nepali words/phrases used in this thesis with their closest meanings and interpretations in English.

that agenda of implementing inclusive education needs to be defined and redefined in partnership with the local stakeholders' (p. 399). To achieve improved educational outcomes for children with special needs in India, Rose (2018b) proposed a similar belief: 'inclusion policies can succeed in providing better opportunities for all learners. But this will require a model of collaboration between policy makers, professionals, activists and families' (p. 3). Similarly, Emerson, Fear, Fox and Sanders (2012) from Australia argue that 'there is little doubt in the literature that parental engagement makes a substantial and positive contribution' (p. 32). Warner (2006), in her book on meeting the needs of English children with disabilities, asserts: 'It is only by listening to parents and taking note of their concerns that professionals can begin to understand the needs of children with disabilities and their families' (p. 1). Parents, local professionals and community members, with their direct experiences with children with disabilities, can provide valuable accounts of children's wellbeing and schooling. This is more important given the context that 'rural perspectives have generally been taken for granted, understated or overlooked' by a wide range of people including academics and policy makers (Henry, as cited in Pini, Carrington, & Adie, 2015, p. 678). Therefore, their experiences and insights are considered foundational for positive outcomes for children with disabilities and improved special needs education provision.

Active engagement of the public or grassroots groups is important in the broader development spectrum as well, as it contributes significantly to local development activities, as argued by Cornwall (2008) in the UK and by Oakley (1995) in Latin America. This is because they possess first-hand authentic knowledge about their situations and are capable of contributing with such knowledge, also referred to as 'folk wisdom' (Bruun & Kalland, 2014). Folk knowledge has 'wide applications to social, political and religious life, linking both the cultural and natural spheres to the same cyclical processes' (Bruun & Kalland, 2014, p. 7). Edwards (2011) and Acharya (2015), who conducted studies in Nepal, also agree with these interpretations as they consider the voices and engagement of grassroots people important on the ground that such engagement mobilises local resources and wisdom and promotes democratic practices.

In Nepal, while I located some studies (see for example, Barriga, 2011; CERID, 2004, 2006, 2008; Dawadi, 2019; Kafle, 2002; Lamichhane, 2013, 2015; Plan, 2014; Regmi; 2017; Shah Thapa, 2012; Thapaliya, 2018; UNICEF, NPC, & New Era, 2001) that have focused on special needs education, they did not, however, include parents' or local communities' experiences and perspectives. Other studies (such as Bista & Carney, 2004; Sharma, 2008; Khanal, 2010, 2013; Tripathi, 2008) have touched upon issues related to community and parent engagement, but they are drawn from only the mainstream education context. This gap in the literature and my own previous experiences of schooling and work within the education sector of Nepal (as I describe below in Section 1.7) and evidence that reveals a lack of parental engagement in the education of their children with disabilities encouraged me to conduct this research.

1.3 Purpose of the research

The main purpose of this research is to give voice to the parents of children living with disabilities in a western region of Nepal and to the community members and local level professionals working closely with these parents. Although the focus of this research is to understand the experiences and insights of parents of children with disabilities, the views of community members and local professionals are also considered with a view to generate additional evidence, whether contrasting with or complementing parents' accounts. To achieve this main aim, the following objectives shaped the research design:

- to understand the experiences of parents in caring for and connecting with the schooling of their children with disabilities in a western region of Nepal;
- to explore the experiences of parents regarding their engagement (or non-engagement) in their children's schooling;
- to explore the perceptions of local professionals and community members regarding the engagement of parents of children with disabilities with schools;
- to identify and analyse enabling and restrictive factors associated with parents' engagement with the schools; and
- to determine whether these findings can contribute to improving policies and practices in the provision of special needs education in Nepal.

To achieve these aims, it was fundamental to engage at length with the parents of children with disabilities, community members and local professionals, as the research participants. The participants in this research were connected to three integrated schools in rural areas of a western Terai district – one of the poorest districts in Nepal (a detailed account of the research site and participants is presented in Chapter 3).

1.4 Research questions

The main question and sub-questions guiding this research are:

1.4.1 Main question

What are parents' experiences of and perspectives on caring for their children with disabilities and attempting to connect with their schooling in a western region of Nepal?

1.4.2 Sub-questions

- How do parents describe, understand and feel about their experiences of caring for and connecting with the schooling of their children with disabilities in a western region of Nepal?
- What are professionals' perspectives on parental engagement in the education of their children living with disabilities in this western rural context?
- What are enabling and restrictive factors associated with parents' engagement with schools?
- How can the outcomes of this research contribute to improving policies and practices for improved educational options for children living with disabilities and parental engagement in Nepal?

1.5 Need for/significance of the research

My initial search of the literature when I was deciding the focus for this study revealed no previous research exploring parents' perspectives on special needs education in Nepal. Most theories and models relating to parental experiences and insights are drawn from western societies. Even studies from developed countries, such as Afolabi (2014) and Trainor (2010a), have identified a need for more systematic research focusing on the benefits of parental engagement in the education of children with special needs; this research therefore is intended to contribute to the knowledge gap in both the international and local contexts.

Although research findings from other contexts including the West can be relevant to the situation in Nepal, there is a need to be aware of specific cultural and contextual differences such as economic status, geographies, the distance to schools and the resources available in schools for children with disabilities. The experiences of the West in their journey towards inclusion including the benefits that can be gained from listening to the voices of parents and local communities can be useful lessons for countries like Nepal, where the inclusive movement is a recent phenomenon. However, the different needs of developing countries and that of local contexts need to be appreciated. Hammad and Singal (2009) along with Mukhopadhyay (2009) state that, while the current focus of special needs education in the West is on ensuring the rights of children with disabilities, and offering an appropriate curriculum and learning environment, the focus in the East is on access to schooling, entry, infrastructure, human resources, struggles to face challenges posed by societal perceptions about disability and so on. Rose, Doveston, Rajanahally, Jament and Visser (2013), following research in India, assert:

> attempts to transport a westernised approach to education to cultural contexts which differ greatly from those in which inclusive schooling has been advanced … may prove to be an inhibiting factor rather than a means of promoting the inclusion agenda. (p. 1)

To understand parents' and local communities' interactions and engagement with the services available for children with disabilities, which are very much influenced by the unique characteristics of Nepali society, we require local and contextual wisdom (Hammad & Singal, 2009; McKenna & Millen, 2013; Rose, 2018b; Sharma et al., 2016). Any research that aims for a deeper exploration of complexities and contradictions of a phenomenon must be grounded in contextual realities (Sharma et al., 2016). Nepali society is a complex mix of poverty, illiteracy, hierarchy-based power relationships, unique cultural practices such as the caste system, and varying values and perceptions about the role of education in society (Bista, 1991). Discussing research in rural contexts, Pini et al. (2015) stress: 'we need research in which rural people's voices and experiences are heard and documented, and the particularities of their communities are detailed and considered' (p. 678). Therefore, this research explicitly recognises parents, community members and local professionals situated in their local culture and context as knowledge creators to investigate how such unique features of Nepali society contribute to parental engagement in Nepal (Finlay & Evans, 2009; Liamputtong, 2007). Moreover, as parental engagement also seems to be compatible with westerners' non-hierarchical, non-authoritarian or egalitarian society, it is not known the degree to which parental engagement would find a place within a hierarchical and authoritarian society such as Nepal.

Moreover, in Nepal, interactions are relational, comprising layers of relationships, governed by social structures such as caste, occupations and class as well as religious and cultural practices and beliefs (Barriga, 2011; Whitman, 2007). Guided by the aim to understand these layers of relationships embedded in the social, religious and cultural facets, as well the researcher's personal belief about reality and the ways to obtain or create knowledge, this research is underpinned by the relational-centred ontology and epistemology. Relational-centred ontology holds that reality or our beingness is very much shaped by our relationship with environment or others, and the relational epistemology views knowledge as the construction, generated through the interations and relations of people with others (a further discussion on these ontological and epistemological accounts is presented in sections 3.2.1, 3.2.2 and 3.2.3 in Chapter 3).

The research strives to tell the untold stories of local people situated in rural and disadvantaged settings through highlighting stories of people and importantly their perspectives and voices on what they believe would make things better and change their lives (Ganz, 2001; James, 1996; Pini et al., 2015). The experiences sought from participants in this study are not viewed as 'objective' realities or facts as such, but rather as active constructions of participants, influenced by their interactions with the world. The aim is to understand how participants make meaning of their experiences of the world as well as to value different ways of knowing and folk wisdom (Romm, 2016). Participants in this research are living in an environment where multiple agencies and viewpoints interact. Therefore, an ontological position that includes the viewpoints of all people involved and tries to see the world through their eyes including those who are at risk, marginalised and unheard is needed for this research. For this, a relational approach is used to access participants in the field, encourage their active participation and prioritise their voices, while and a narrative approach is employed to presenting and analysing the data as the use of a narrative approach aligns with the storytelling culture of Nepali society, as it serves as 'ways of understanding and acting upon reality' in Nepal, as observed by Davis (2014, p. 1).

As this research intends to generate expanded understandings of issues related to parental engagement in the contexts of special needs education in Nepal, it is hoped that it will be valuable for researchers in the field of disability and special needs education and for those who wish to understand the concerns of parents from the perspectives of parents themselves, local personnel and community members. Moreover, it is expected to help explore tensions that occur between home and school and understand how these tensions impact the education of children with disabilities. Further, the findings of this research will be relevant for policy makers, future researchers and special needs educators. This research is also expected to support local service providers including schools to better address the needs of children with disabilities and their parents.

1.6 Structure of the thesis

In this initial chapter I have introduced the research background, the purpose of the research, the research questions, the significance of the research, a brief account of the structure of the thesis and at the conclusion of the chapter I provide an *a priori* reflection. In Chapter 2, I review the literature addressing disability, inclusion and education with a particular focus on parental engagement in special needs education. Chapter 3 addresses my methodology and methods. I discuss qualitative methodology, relational-centred inquiry, and the narrative approach to the research. I then provide an overview of the methods employed in the data collection and analysis processes and address ethical issues in the research.

In Chapter 4 I present portrayals of four parents, chosen to represent the diverse caste and ethnic backgrounds of parents interviewed in this research. I offer rich in-depth case-focused portrayals based on their experiences of living with their children with disabilities along with my subjective impressions during the interviews. Chapter 5 details a thematic presentation of participants' experiences and insights. First, I reveal how different themes emerged from (or are grounded in) the interviews with parents and focus group data. The themes were grouped under two main stages of the parental journey relating to two distinct experiences of parents during the early years of caring for their children and later while schooling and educating them. I elaborate on each theme as the parental journeys unfold from one stage to another. Chapter 5 also provides an *in situ* reflection in that I present my experiences and feelings about engaging in the field relating to the choice of research methodology, and different methods and techniques employed for the data presentation.

Chapter 6 is interpretations of the findings. First, I present the key finding and consolidated findings drawn from the themes generated and discussed in Chapter 5. These findings are presented in the form of a ‘story map’, with each finding then interpreted in the light of the research questions, relevant theories and previous works. The final chapter presents discussion, implications and conclusion of the research. In this chapter, insights from the findings and implications for future policies and practices are identified, taking cognisance of different situations, including families, schools and governments. The chapter also discusses the areas deemed important for future research and limitations of the study. I conclude the thesis with a final *posteriori* reflection. Before moving to the review of the literature in the next chapter I offer an *a priori* reflection to provide insight into what I, as an ‘insider’ researcher, bring to this study.

1.7 *A priori* reflection: My own story and impetus for the research

Inspired by the doctoral research of Kinyany-Schlachter (2017), I present a reflection on my own experiences and insights at three different stages of this research: beginning, middle and end. The first, a priori, reflection appertains to my cultural and research background. Mid-way through the thesis I provide an in situ reflection and a final posteriori reflection at the conclusion. These sections will reflect my tacit and developing knowledge as my research journey progresses from the initial phase to the concluding phase.

My impetus for this research arises from my own personal background and professional interests. Grassroots approaches to rural development have attracted me for a long time. It is possible that my desire to see greater empowerment of ordinary people could be related to my own disadvantaged conditions in experiencing poverty, growing up in a remote village, and later, my roles as a teacher and school supervisor in remote locations of Nepal.

I was born in a remote, hilly western district of Nepal, about 500 km west of the capital city, Kathmandu. After completing grade seven in a nearby school, I went to a high school which was two hours’ walk away from my home. I had to commute four hours each school day for three years before

I completed my high school education, which at that time was a grade 10 exam, also known as the School Leaving Certificate (SLC) examination. I then went to Kathmandu to a college for further education. It would take one and a half day's walk from my home to get a bus to Kathmandu in those days. It was very expensive to gain education in Kathmandu and very difficult financially to survive there. Those hard times are still fresh in my memory. In any case I survived, and I passed all the exams I attended, without failing any subjects, and was able to realise the naïve goals that I had at that time such as to complete college studies.

I was brought up in a neighbourhood where the majority of people were from the so-called upper castes, particularly Brahmin and Chhetri, yet they were not wealthy and privileged. With the cultural identities of a male from a Brahmin family and a follower of the dominant Hindu religion, I started and continued my education. This identity was in a certain sense a privilege for me; however, I experienced discrimination and felt hatred during my college life in Kathmandu.

The demarcation between Kathmanduites and us as outsiders in Kathmandu was more obvious at that time. Students from Kathmandu would consider themselves 'sabhya' (significant, civilised, and knowledgeable) and the rest of us from outside of Kathmandu were seen as 'pakhe'[5] *(insignificant, uncivilised, with less knowledge, if not dull). I noticed that we were ignored, and our voices were unheard. While I felt this acutely and was not happy with what was happening, I was a shy student, not the type who joined activist political movements. Deep in my mind lay a desire for change and I wished that anyone coming from a disadvantaged background should be heard, listened to and respected.*

After completing my college education in Kathmandu in the early 1990s, I started my career as a secondary school teacher. I taught mathematics and science to high school students in a remotely located school near my home for two years. Then I applied for a school supervisor position in the mid-1990s and succeeded. It was the time when the role of a school supervisor was changing towards more of a supporter for teachers and schools, as opposed to previously being more of an inspector, monitor or controller. This suited my nature as I wanted to develop positive relationships with teachers through what I would now describe as relational ways of working. As a school supervisor, I found myself once again in rural locations. Over time I became increasingly aware of the importance of participatory practices in development activities. One of my jobs comprised working with parents, communities, school teachers and head teachers to assist them in making their periodic development

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[5] *Pakhe* is Nepali slang that refers to an ignorant, uncivilised person, who does not know the modern world or contemporary events. *Pakhe* literally means a person who lives in a hilly area. However, it is offensive to call someone a *pakhe*.

plans, known as 'school improvement plans' in Nepal. Working with these people, I gained a sense that local people knew more than they were given credit for.

During those years, I witnessed lay people's attempts to bring change in several aspects of their lives in rural areas, such as education, drinking water, forest conservation and income generation. I can recall some parents volunteering to work in schools, for example assisting schools by cooking meals for students for the Free Meals Program that was launched by the government in the poorer areas. In other cases, some parents contributed their labour to build infrastructure for their children's schooling. Yet it often seemed as if they were holding back, unsure of how to help; and I could see that they needed to be encouraged and assisted to contribute. I had a glimmering sense of these people's potential. At that time, I thirsted to know more about what makes people become motivated in such voluntary services. I began to form the view that only by creating an opportunity for the voices of these people to be heard can we benefit from their knowledge. However, I felt like this view of mine was not shared by my colleagues and other professionals working in the villages.

During the early 2000s, I undertook an evaluative study, as part of my Master of Philosophy (MPhil) degree,[6] *with an aim to explore school procedures for involving parents and communities (Pokhrel, 2004). My sense that the local wisdom of grassroots people was not valued was supported by the findings from this small study, and this was later confirmed through my work with the Department of Education (DoE). My role with the DoE involved drafting policies and plans, operational guidelines, and the funding allocation for the entire education system, including special needs classes throughout the nation. I dealt with a range of stakeholders including the National Planning Commission (NPC), Ministry of Finance (MoF), donor communities, as well as academics, curriculum professionals, teacher educators, principals and teachers. Despite there being considerable participation by different stakeholders at the macro level, I found a distinct lack of involvement by local people, including parents. The voices of ordinary people were absent. I became aware of a tension arising within me and I realised there was a clear gap between my passion and my existing work environment. I began to wonder: would parents come to their children's school and engage in school activities if they were invited and felt welcome. I became eager to know how they would respond to an invitation to engage with the schools, and what they would like to get out of such experiences.*

On looking back to my childhood experiences again, my young mind was inculcated by many prevailing societal norms: caste, religion, gender and so on. During my early childhood, for example,

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[6] I received a scholarship from the Danish Government to undertake this degree at the Danish University of Education, Copenhagen, Denmark; in June 2007 the university merged with the University of Aarhus.

my parents used to tell us that, 'If you happen to touch (or are touched by) Dalits you need to purify yourself by sprinkling sun-pani (water touched with any piece of gold)' – the practice known as 'sun pani chharkarne' or 'chhoi chhito halnu parne'. Most of my neighbours were Chhetris, who were considered lower in the caste hierarchy than Brahmins. There were Janajatis (indigenous people) in my village, who belong to the casteless system, but they were also considered lower in the Hindu caste-based system. Such caste-based practices were clearly a barrier to so-called lower caste people participating in mainstream/public activities (such as ward/mass meetings, discussions and so on) including schools. The practice would also prevent them from raising their voice. As such my caste identity was not a limitation to my public participation in the village and in schooling, although, as I could remember from my childhood, I had deep feelings about the people from so-called lower castes. I would imagine myself in their shoes and would consider how difficult it would be to experience such discrimination.

In addition, I could clearly visualise that my identity as a boy (male) also favoured me to achieve a certain level of education from my home district and later to make my way to Kathmandu. My own sister had to leave schooling without completing even grade 8 due to the burden of household chores, imposed on her as a girl but not on the boys in my family and also due to the presence of the gender stereotype in my own family that girls, as caretakers of the household chores, do not need education. This indicates that if I was a girl from a lower caste this story would have been different, given the constraints imposed on girls and lower-caste people in the society at that time.

Similarly, my religious background coming from a Hindu family, which is a dominant religion of Nepal, tied in with the caste-based system, gave my parents and me a sense of the benefits of getting an education, even though my education was not related to Vedic traditions. A Vedic education was generally supposed to be beneficial for Brahmins as they could become gurus in their later life and could easily make a living by preaching on Hinduism or offering priestly services such as carrying out rituals for other people. My parents might have equated general or modern education with a Vedic education, maybe because at the time of my early education (the late 1970s) modern schooling in the country was being implemented. In this way, being a boy from a Brahmin family who followed the Hindu religion contributed significantly to forming my identity. However, when I came to college in Kathmandu, I could no more enjoy the privileges acquired through my cultural identity. For example, I noticed that there was less caste-based discrimination among college students; however, it was still a pronounced practice within local people and communities even in Kathmandu. I felt more discrimination on the basis of wealth and geography. This could be because, though Brahmin is a high caste in a so-called caste-based system, people from a poor family or from a rural area had a *lower status. There was a difference in status between rural and urban people. Later I realised that discrimination or prejudice is not only induced by caste, culture or gender; it has multifaceted dimensions, including geography, ability, health, wealth, employment, citizenship, education, training, to name a few. This made my time studying in Kathmandu very difficult. Overall, the experience I had in Kathmandu contributed to developing my passion in the focus areas of this research.*

As I was eager to learn the practices used to engage parents and communities in schools in developed countries, I began to think about pursuing a doctoral degree from overseas. With my networks that I built while working with the Department of Education in Kathmandu, I came to learn that the Government of Australia provided scholarships for Nepalese scholars to pursue doctoral degrees. I took part in the scholarship selection process and was selected. Initially, I thought of exploring parental experiences in mainstream education contexts. However, as I went through the academic literature on parent engagement with schooling in developing countries and Nepal, I realised that there was an even larger gap in research about parental voices in relation to special needs education. Therefore, I decided to undertake a study aimed at understanding the experiences and insights of parents of children with disabilities, along with those of locally situated people, with a view to bring their voices and concerns to the fore. While I particularly wanted to elicit the voices and experiences of the parents, I also wanted to learn and hear from community members and local professionals for a more holistic understanding and to create a safe space in which to draw on their ideas and understandings. In this way, being inspired and encouraged by both my personal and professional backgrounds, I decided to commence this research with a view to developing new insights to contribute to the knowledge gap regarding parental experiences in relation to caring for and connecting with the schooling of their children with disabilities.

CHAPTER 2 - LITERATURE REVIEW: MAPPING THE TERRITORY

> Human beings are not built in silence, but in word, in work, in action-reflection. But while to say the true word – which is work, which is praxis – is to transform the world, saying that word is not the privilege of some few persons, but the right of everyone. (Freire, 1970, p. 88)

2.1 Chapter introduction

This literature review examines the concepts, theories and scholarly works of relevance to my research questions with a specific focus on parental experiences of raising children with disabilities and how those experiences influence their engagement with their child's schooling. Key themes include stress and grief, resilience and coping strategies, challenges of choosing (or not choosing) schooling options and factors that influence the levels of parental engagement. I also present a historical account of parental engagement in Nepal and an overview of research from Nepal in relation to parents of children living with disabilities. However, I commence the literature review focusing on conceptions of disability, inclusion and education. Exploring how disability, inclusion and education are perceived across cultures and particularly in Nepal, and how they interact with each other, provides important contextual information to situate parents' experiences and engagement with educational services. This section also considers how disability is framed within the broader inclusion agenda and its subsequent impact on families of children living with disabilities.

2.2 Conceptualising disability, inclusion and education

2.2.1 Making sense of disability

According to the United Nations (UN, 2017), 'there is no uniform definition, often confusion on what constitutes a disability, and methodologies used across countries are inconsistent when collecting this type of information' (p. 2). Similarly, WHO (2011) maintains that 'disability is complex, dynamic, multidimensional, and contested' (p. 3). However, several nations, including Nepal, define the term 'disability' by drawing on the definitions which appear in the documents/declarations of WHO and the United Nations Educational Scientific and Cultural Organization (UNESCO) (UNESCO, 1994, 2006; WHO, 2011). The Nepalese government defines disability as:

> the condition of difficulty in carrying out daily activities normally and in taking part in social life due to problems in parts of the body and the physical system as well as obstacles created by physical, social and cultural environments, and by communication. (GoN, 2007, p. 2)

This definition acknowledges that disability is associated with both individuals and the broader society, and these varying perspectives will be discussed shortly. Until 2007 the Nepalese government recognised only four types of disabilities, namely, physical, mental, visual and hearing

(GoN, 1982). To reflect worldwide developments the government later included seven types of disability (GoN, 2007) and this finally increased to ten types in 2018, with the addition of psychosocial, haemophilia and autism as new types. The current categories of disabilities officially recognised in Nepal (CEHRD, 2018) are:

- physical disabilities
- visual impairment or blindness
- hearing impairment or deafness
- communication disorders involving voice and speech
- psychosocial impairments
- intellectual disabilities
- haemophilia
- autism
- multiple disabilities.

According to severity, each of these types is divided into four categories: profound, severe, moderate and mild. Figure 2.1 depicts the types and categories of disabilities recognised in Nepal. However, the language used in the dot points above does not reflect the actual terms used in the government document (as given in Figure 2.1), showing that Nepal is still in a developing state of knowledge about disabilities. For example, while autism was previously a subcategory of intellectual disability, it is now recognised as a separate type.

Types	Categories (severity)			
Physical disability	Profound or complete	Severe or high	Moderate or medium	Mild or near 'normal'
Disability related to vision – blindness, complete vision loss, and low vision				
Disability related to hearing – deaf, and hard of hearing				
Deaf-blindness				
Disability related to voice and speech				
Mental or psychosocial disability				
Intellectual disability				
Haemophilia – bleeding disorder				
Autism				
Multiple disability				

Source: adapted from CEHRD (2018, pp. 1–2).

Figure 2.1: Types and categories of disabilities in Nepal

2.2.2 Perspectives about disability

The research literature on disability is expansive and reflects varying epistemological stances. Historically, disability has been of significant interest to many including those from religious backgrounds seeking to link disability with religious beliefs through to sociologists who propose that society is the foundation of disability (Retief & Letšosa, 2018; Slee, 2019). For the purposes of this research I will restrict the review of literature to briefly summarise the following three major perspectives, often referred to as models, on disability, particularly as they relate to the thesis (Brandt, 2015; Oliver, 1995; Oosterlee, 2012; Pearce, 2009):

- moral/religious/traditional
- medical/biological
- social/political.

These perspectives were adopted by Nepali scholars Kafle (2002), Lamichhane (2015), Regmi (2017), Shah Thapa (2012) and Thapaliya (2018) in their research on disability and hence are of relevance to research in Nepal. In practical terms, the lines of demarcation among these perspectives may not always be clear, because each model or perspective intersects with the others in terms of beliefs, causes and interventions (as discussed below in more detail), with aspects of the varying perspectives being discredited as others gain momentum. Currently, in developed countries there is a strong focus on the social/political model of disability as disability advocates gain greater attention through the media, government policy and initiatives, and legal standing. However, this is not as evident in Nepal where the traditional and medical models take precedence. The following is a succinct review of the three areas particularly in relation to Nepal and this research.

Moral/religious/traditional perspective

The moral belief about disability is rooted in traditional spiritual, religious or cultural practices. It is still a dominant paradigm in many societies including Nepal (UNICEF et al., 2001; Barriga, 2011). It draws on past beliefs that perceive disability as a deficiency. According to Lamichhane (2013) this perspective considers disability as an incapability or inefficiency of an individual that might have been caused by some supernatural force or metaphysical cause. Such causes could vary from the fate of the person, destiny, evil-eye curses or the price believed to be paid by parents for their past misdeeds or sins (Lamichhane, 2013). It views disability as an individual or family problem.

Hindu-dominant societies such as Nepal often attribute disability to the notion of *karma* (Whitman, 2007). *Karma* is a law of cause and effect, which is exemplified by the maxim ‘as you sow, so you reap’. This means that it is believed that everyone is bound to bear the result of his/her actions. The wheel of *karma* (the result of an action) can even transcend a person's physical life (Bilimoria, 2007; Sarvapriyananda, 2018) and yield the fruitions of one's action in one's future life/lives. According to a study from the early 2000s, approximately 28% of the Nepali population adhere to belief in *karma*, indicating that disability is linked to the family's fate (UNICEF et al., 2001). There is a likelihood that this percentage may be higher in remote regions of Nepal where religious and cultural practices remain more traditional. This research provides an opportunity to determine whether the participants continue to adhere to such beliefs.

The moral perspective tends to ignore the need for any intervention. While it helps people make sense of what they believe is their misfortune, it often raises their level of acceptance and resilience beyond their initial grief and to devise coping strategies. Such traditional thinking and responses are due to viewing disability as an unavoidable condition and so there is limited faith in scientific or social attempts to improve the situation for the family or the child/person (Whitman, 2007). Instead, a child or person with a disability may be viewed as a passive recipient of charitable services requiring support from others. They are viewed as unfortunate rather than having capacity, with the family and society being held responsible for their ongoing needs and care (Goodley, 2011; Lamichhane, 2015).

Medical/biological perspective

The medical model views disability from a physiological perspective, focusing on people's level of impairment and physical health (Mittler, 2005). The shift in focus to the medical model increased in the mid-18th century due to rapid developments in scientific reasoning and industrialisation in Europe (Retief & Letšosa, 2018). The medical perspective views people with disabilities as deficient and in need of medical intervention. As Taderera and Hall (2017) stated, 'individuals need to be "fixed", which promotes dependency, charity and sympathy' (p. 2). Experts and professionals are expected to remediate the deficiencies of children/people with disabilities by intervening surgically and through therapy using scientific knowledge and tools (Rieser, 2012). The power lies in the hands of the medical profession and their advice is rarely challenged by families. This often results in families believing their child has little capacity to develop and that they are best confined to a specialised home or service. The removal of children with disabilities such as physical, vision, hearing or intellectual impairments to 'homes' specialising in the 'treatment' of such children was common in western countries through to the mid-1950s (Turnbull & Turnbull, 1985). Treatment often involved 'specialised education services' conducted by medical professionals and specialised teachers, for example, teachers of the deaf who used sign language (Read & Walmsley, 2006). In this model the medical professionals held the power while parents were relatively powerless and often accepting of their child being removed. While attitudes have changed significantly in developed countries, the imbalance of power between medical professionals and parents is of relevance and interest to this research. In addition, medical beliefs about disability in Nepal often co-exist with moral beliefs (Maudslay, 2014) and this research provides an opportunity to determine whether this continues to be the case.

Social/political perspective

According to the social perspective, all individuals are valued members of society having full rights to participate in their environment (Carrington, 1999; Oliver, 1995; Samaha, 2007; Sullivan, 2011). Within this construction of disability, the problems or limitations are not seen to lie within the individuals but within the society or its structures. Taderera and Hall (2017), citing Oliver (one of the early exponents of the social model of disability) opine that the social perspective is ‘an instrument to gain insight into the manner in which society disables people with impairments’ (p. 2). Sullivan (2011) has a similar view:

> The view that people with disabilities are inferior, or in need of a cure to become ‘normal’, is rejected. Rather than designating the individual’s impairment as the source of the problems associated with disability, this model locates the source within society. (p. 3)

The social perspective argues that ‘disability is everything’ that causes isolation and exclusion for people with disabilities including ‘prejudice and discrimination, inaccessible buildings and transportation systems, segregated education, and so forth’ (Sullivan, 2011, p. 3). To this end, the external conditions, lying within the social, cultural, economic, psychological and political domains, become powerful in the life experiences of people with disabilities (Goodley, 2011; Slee, 2014).

The social perspective calls for changes in social attitudes, policies and the environment to address the needs of everyone, without giving special privileges to some (people *without* disabilities) and restricting those with disabilities (Carrington, 1999; Lamichhane, 2015; Peters, 2004; Sullivan, 2011; Taderera & Hall, 2017). Unlike the medical model, the social perspective ‘promotes independence and stimulates potential in persons with disabilities’ (Taderera & Hall, 2017, p. 2) and promotes the right of all people to be included in all aspects of society. One of the educational responses to the social perspective of disability is inclusive education, which is designed to accommodate all students in the same school no matter what their individual needs are. This research will be listening for evidence of parents’ understanding of a social perspective on disability and beliefs that their children should be included in mainstream education in Nepal.

Table 2.1 provides a summary of the three perspectives of disability and the interventions envisaged by each perspective. For example, the response to the moral perspective is generally charity-based intervention or no intervention at all, that is, exclusion. The third column of the table depicts the interventions pictorially. While the moral or traditional perspective generally anticipates no intervention or exclusion, the medical perspective has two types of intervention – segregation and integration – and the depiction corresponding to the social/political perspective demonstrates that services for persons with disabilities are fully integrated with services for everyone else. The final column reflects the most relevant educational models associated with the different perspectives on disability.

Table 2.1: Perspectives on disability, interventions and educational approaches

Model	General intervention	Depiction	Education approaches
Moral/traditional: disability as an individual/family problem caused by supernatural forces or past sins. High acceptance or resilience level	Charity-based interventions or no intervention (**EXCLUSION**)		No school or charity-based schools
Medical/biological: personal problem caused by physiology (physical, sensory, mental). Experts are expected to fix it	Specialised expertise to be provided in isolation within mainstream services such as separate hospitals/ schools (**SEGREGATION**)		Special schools: special educators, special curriculum
	Specialised expertise to be provided along with mainstream facilities (**INTEGRATION**)		Integrated schools: at a mainstream location but in separate units
Social/political: social, cultural or organisational structures as barriers	Interventions embedded within mainstream services, no discrimination (**INCLUSION**)		Inclusive schools: all are welcome, and diversity is valued. Individual students' needs are addressed

Source: adapted from Petrie, Devcich and Fitzgerald (2018); Rieser and Rickell (2007); Rieser (2012); WHO (2011).

In practice, however, these perspectives and their corresponding interventions are not as distinct as they appear in Table 2.1; rather they blur, overlap and intersect. Although discussion and understanding of the distinct perspectives assists with conceptual clarity and comparison, a single perspective in isolation is rarely evident in practice. In addition, a single perspective rarely meets the needs of all families and their children, as different families bring specific cultural and/or religious beliefs and aspirations, which is of specific relevance to this research. This condition therefore implies a need for a more holistic understanding of disability as discussed below.

Cultural-contextual view of disability

An additional perspective, sometimes integrated under the social perspective, is a cultural-contextual perspective encompassing an eclectic view that interacts with the previous three perspectives on disability (Ainscow & Sandill, 2010; Hickey & Wilson, 2017; Maudslay, 2014; Sharma et al., 2016). According to Pearce (2009), 'context, location and culture play an important role in how disability is understood' (p. 28). A cultural-contextual perspective can be useful in considering the socio-cultural and religious needs of communities because it acknowledges varying viewpoints and attempts to bring them together (Rose, 2018a, 2018b; Sharma et al., 2016). For example, it does not simply disregard moral beliefs about disability, ascribing those beliefs as superstitions. Even moral beliefs can be useful as they might shape the way people approach, respond or deal with disability; they might help them to become resilient and manage their grief, especially when there is a lack of any external support and services accessible to them. Similarly, the medical belief is considered to be relevant for those who require access to 'therapy, medicine, surgery or special treatment' (Peters, 2004, p. 19), while the social perspective has gained momentum in recent times as people with disabilities advocated for their rights. This implies that an understanding of all the perspectives is crucial to ensure the needs of people and cultures are prioritised rather than imposing something that is not culturally appropriate (Rose, 2018b). Maudslay (2014) highlights the importance of and need for such a view of disability in Nepal given the diversity of contextual conditions found in the country. As this research is situated in a western rural area of Nepal, it provides an opportunity to determine if all perspectives are evident in the stories of research participants or whether some are more prominent than others and, if so, why this might be the case.

2.2.3 Inclusion and the role of education in promoting inclusion

The concept of inclusion places at the forefront the right of everyone to a dignified life so that each individual can fully participate in society (Pearce, 2009; Goodley, 2011; Singh, 2009), as well in schools (Brandt, 2015; UNESCO, 1994). It recognises that every human being, regardless of any differences or labels attributed to him/her, deserves to be a valued member of society, able to contribute to his/her community. Hooja (2009) defines an inclusive society as 'one where everyone is valued, respected, accepted and given equal opportunities; one where there is no differentiation and discrimination on the basis of gender, race, caste, class or disability' (p. 353).

The focus on and recognition of human rights, empowerment and equality of disadvantaged people from the mid-1960s to the early 1970s in the western world resulted in policies and reforms to address the social, economic, political, cultural, relational and psychological barriers which served to marginalise different groups in society (Goodley, 2011). With heightened awareness of forms of discrimination there was a move towards assertive action to include disadvantaged and marginalised people in all aspects of society including access to education and employment, although there have been varying degree of success, as people with disabilities are still underemployed and many students with disabilities still attend specialised schools (Slee, 2019).

Social justice and human rights movements have served as a foundation of the move toward greater inclusion for all. Armstrong, Armstrong and Spandagou (2011) present three values of inclusion: equity, social justice and human rights. Foreman and Arthur-Kelly (2014) present a similar set of driving forces attributable to inclusion: social justice and human rights movements; UN declarations and legislation; and research findings. Rieser and Rickell (2007) summarise the values and driving forces behind inclusion and present these as principles of inclusion.

Principles of inclusion

All people

- have a voice and a right to be heard
- have a right to belong and to be a part of their community
- have a right to education and lifelong learning
- have a right to friendship and meaningful relationships
- bring gifts to the world
- have the ability to contribute and share their gifts and abilities
- have the right to a valued life
- have dreams and aspirations.

Source: adapted from Rieser and Rickell (2007, pp. 46–47); Rieser (2012, p. 47).

However, building such values in society is not an easy task as it requires a change in people’s attitudes, beliefs, behaviours and everyday practices (Cologon, 2013; Foreman & Arthur-Kelly, 2008; Kalyanpur, 2008; UNESCO, 2009b). Therefore, efforts to include people with disabilities, for example, need to take into account a range of factors including individual and institutional discrimination, accessibility of public buildings and transport systems, workplace adjustments, access to education and importantly attitudes (Oliver, as cited in Oosterlee, 2012). According to Cologon (2013) such change is not a one-time activity; rather it is a long-term developmental journey, and this is of particular relevance when communities have centuries of religious and cultural beliefs driving their way of life.

The meaning and practice of inclusion may vary between countries and regions due to different social and cultural beliefs and economic contexts. For example, in Nepal, gender and caste systems are powerful contributors to exclusion, and so a girl with a disability from a so-called low caste is likely to face triple exclusion induced by her gender, caste and ability (Dawadi, 2019; Shah Thapa, 2012). In such a context, the mere participation of excluded members in society does not guarantee true inclusion. As Cologon (2013) argues, ‘To address such exclusion may require sensitive approaches that consider the context and needs of the targeted people’ (p. 13).

Education is believed to be central to the development of inclusive societies (UNESCO, 2009a). Lamichhane (2015), a Nepali scholar with a visual impairment, considers ‘education as the first step to bring about change’ (p. x). Similarly, Oosterlee (2012), in her research from Nepal, asserts that education for children with disabilities is crucial in supporting greater independence and full participation in society. Providing education to all children including those with disabilities is therefore considered the duty and responsibility of every nation, although in reality they remain the group who is the most excluded from education across the world particularly in developing countries (ECDC & VSO, 2015; UN, 1989; UNESCO, 1994, 2006).

Australia, as a developed country, adopts a rights-based approach to education to ensure the equal and meaningful participation of children irrespective of their perceived capability, colour, creed/religion, race, gender and location (Forlin, 2013; see also Carrington, 1999). The European context is similar: ‘Inclusion in education is recognised as a basic human right and the foundation for a more just and equal society’ (European Agency for Development in Special Needs Education, 2012, as cited in Forlin, Chambers, Loreman, Deppler & Sharma 2013, p. 7). However, despite inclusive education having been promoted as the basis for creating more inclusive societies, special education continues to fall short of these promises in many developed countries (Slee, 2019).

Developing countries including South Asian countries such as India, Pakistan, Bangladesh and Nepal have also adopted rights-based approaches to education, at least in theory, in recent years, especially after the advent of the new millennium (Rose, 2018a, 2018b; see also Acharya, 2007; Kalyanpur, 2008, 2009). However, it is not always reflected in practice and the pace of Nepal’s move towards inclusion is reported to be slow (Acharya, 2007; CERID, 2008; Kafle, 2002), as is the case in India, as described by Rose (2018b).

The challenges in providing special needs education to all children with disabilities are many and this is discussed in more detail below, but it is evident that special needs education is yet to be well understood or resourced in remote and even most urban areas of Nepal. This is not surprising given that the overall education system in Nepal is challenged by insufficient resourcing and lack of quality infrastructure.

2.2.4 Different approaches to the provision of special needs education in Nepal

As also indicated in Chapter 1, three types of education approaches, namely special, integrated and inclusive schools, are evident in Nepal for educating children with disabilities (Shah Thapa, 2012; Kafle, 2002; Lamichhane, 2013, p. 312; DoE, 2015). The same types of provisions also prominently appear in international literature (Forlin, 2006; Foreman & Arthur-Kelly, 2014). An overview of the concepts and characteristics of each of these provisions is provided here, along with a brief account of how each of these are being initiated and practised in Nepal.

Special education

According to Forlin et al. (2013), special education originally referred to education provided in a separate or segregated setting. Special schools traditionally served students with moderate to severe disabilities with specific standards for entry (Forlin et al., 2013). Influenced by the medical model of disability, this approach was based on the view that children’s needs could better be addressed by expert teachers who had specialised knowledge of special education and who could help children develop at their own pace (Carrington, 1999). It requires, according to Rieser and Rickell (2007), schools to be equipped with appropriate devices, technology, and teachers with specialised expertise. However, in the modern context, special education has come to mean something broader, as it can be provided in mainstream schools in an integrated or inclusive setting. In developed countries, the use of specialised technology and resources along with differentiation of curriculum and instruction designed to meet the needs of individual students more closely defines special education, especially given that the majority of students identified as having a disability attend mainstream schools (Foreman & Arthur-Kelly, 2014).

Although the majority of students with disabilities are attending mainstream schools in developed countries, special schools still exist, and they are often populated with students with severe and complex disabilities. Special schools are increasingly viewed as being problematic in that they are isolating children with disabilities from mainstream educational opportunities and models of socialising within the wider community (Carrington, 1999; Slee, 1998). For example, Forlin et al. (2013, p. 21) found that in an Australian context ‘attending a separate special school separates students often physically as well as educationally from their local mainstream school'. Such separation at school is not desirable, because 'children who are marginalized at the school level remain marginalized from society' (Hooja, 2009, p. 353).

In Nepal, as described in the *Education Act*, 'special education means special types of education to be given to children who have visual, hearing, physical, intellectual or mental disability' (Nepal Law Commission [NLC], 2010, p. 4, my translation). In practice, each special school in Nepal is focused on a specific type of disability. Further, these education programs address mostly the four types of disabilities that were recognised officially in 1982 (GoN, 1982); however, the Ministry of Education commenced additional programs for children with cerebral palsy and autism from the year 2011 (Dhungana, 2014).

Before the advent of special schools in the mid 1960s in Nepal, children with special needs were not able to access schooling (Kafle, 2002). In 1964, the first special school was established in Kathmandu. This was a laboratory school for children with visual impairment operated by the College of Education, Tribhuvan University. The Special Education Council was established in 1973 with a mandate to manage special education overall.[7] Special schools offered education for children with disabilities in an isolated way (CERID, 2008). Gradually other schools for students with other types of disability were opened across various parts of the country; however, the numbers of these schools grew slowly. Nationwide, there are now 34 special schools spread across 19 of the total 77 districts of Nepal (DoE, 2015). Of those 34 schools, 16 are schools for students with visual impairment which recently merged into mainstream schools.

Integrated education

Integrated schools are mainstream schools which include a special unit or class located on the same site (Forlin et al., 2013). Integration as such is a 'process of transferring a student to a less segregated setting than in special schools' (Foreman, 2014, p. 18). In some cases, students can spend part of the school day such as break times in a mainstream classroom or schoolyard with their peers without disabilities (Forlin et al., 2013).

Nepal began creating integrated schools in 1993 by establishing 180 centres within selected mainstream schools in 23 districts, under the Basic and Primary Education Project (1992–97). Later,

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[7] The functions and mandates of the Special Education Council are: to approve grants to conduct special education; to implement the special education curriculum, having received approval from the Curriculum Development Centre; to determine procedures of examinations for special needs children; to coordinate, manage, supervise, control and inspect special education institutions/schools; and to prescribe criteria relating to financial grants to be given to community schools to conduct special education (Nepal Law Commission [NLC], 2002).

this model, known as a resource class, was expanded to 380 centres covering all districts (CERID, 2004; Lamichhane, 2015; NLC, 1996, 2010). One of the teachers from the regular teacher cadre in the school would be assigned as a ‘resource teacher’ to take the sole responsibility of the resource class. These teachers would also receive specialised training for 10 to 45 days focusing on one particular disability type that they are anticipated to work with. In addition, each resource class accommodates about ten students with disabilities (CERID, 2008; Regmi, 2017; Thapaliya, 2018). Integrated schooling in Nepal is credited with bringing children with disabilities into resource classes within regular schools. In recent years, increasing number of parents are enrolling their children with disabilities in these integrated schools (CEHRD, 2018). Students in integrated schools share spaces during recess, like in Australia. However, these schools operate with a slight variation in Nepal in that each integrated school serves students with only one specific type of disability. This type of school generally provides basic hostel-style residential facilities for students with disabilities. Residential schools for children with disabilities, while becoming significantly less common in developed countries, are still the norm in Nepal. This is due to the fact that suitable schools are often a great distance from the family home and there is a culture of families selecting schools with hostel facilities if they are seeking an improved educational opportunity for their child beyond the local school. The hostel is run by an *aaya* (caretaker) who cares for the children after school hours (Acharya, 2007; Kafle, 2002; Regmi, 2017).

The objective of integrated programs is to prepare students to take part in mainstream education after some years of education in resource classes (CERID, 2006). However, in these settings it has been observed that students rarely have a chance to mix with their peers without a disability (CERID, 2008).

Inclusive education

Inclusive education is education for children with disabilities provided in the regular classrooms of their local school (Morton, 2012; see also de Boar et al., 2010; Yssel, Engelbrecht, Oswald, Eloff, & Swart, 2007). It is based on the view that all children should have access to education in ‘close proximity to their homes’ (Miles, Miler, Lewis, & Kroft, 2002, p. 25). However, in the broadest sense, inclusive education calls for the elimination of all types of obstacles to education so that all children, irrespective of their limitations or privileges, have an opportunity to access a relevant education and participate in school activities (Carrington, 1999; Carrington et al., 2012; Sharma et al., 2016).

Full participation of every student is considered the key to inclusive education. According to Underwood, inclusive education means the placement of students with disabilities in mainstream schools ‘with full participation in curriculum and classroom activities’ (cited in Forlin et al., 2013, p. 21). Beveridge (2005) in the UK also asserts that ‘inclusive education must be concerned with the dual processes of maximising participation and reducing exclusion’ (p. 107). Nepalese authors (Acharya, 2007; CERID, 2004; Kafle, 2002; Regmi, 2017) equally emphasise creating a culture in which all children can equally partake in all activities in the mainstream environment (CERID, 2008).

The Government of Nepal conceptualises inclusive education as a measure to incorporate into the mainstream schooling system not only children with disabilities but also all disadvantaged and marginalised children including *Dalits*, ethnic minorities, the socio-culturally oppressed, conflict-affected children, and children from language minorities and remote areas (CERID, 2004, p. 36). It is in line with the stated aim of inclusive education in Nepal ‘to educate all types of children without making any discrimination’ (CERID, 2006, p. 1), although this appears to be ambitious given existing resources and socio-cultural contexts. According to Regmi (2017) and Thapaliya (2018), the policies aim to create learning opportunities for children who are denied education, due to various situational causes, or are at risk of dropping out from school due to the lack of an adaptive and accessible environment and support system. However, the policies are not always translated into practice. This current research, through exploration of families’ experiences of accessing education for their children with disabilities, will provide evidence of how and whether current policies are being translated into practice in Nepal.

2.3 Parents’ experiences of raising their children with disabilities

Internationally, there is extensive research on parental experiences of raising children with disabilities (Cauda-Laufer, 2017; Cuzzocrea, Murdaca, Costa, Filippello, & Larcan, 2016; Jack, 2016; Kurtzer-White & Luterman, 2003; Seligman & Darling, 2007; Turnbull et al., 2013); however, literature from Nepal is sparse. Some research conducted in Nepal, such as Singh and Ghimire’s (2017) study, only focuses on ‘statistical association between socio-demographic characteristics of parents and stress level’ and ‘correlation between stress and coping strategies’ (p. 1), rather than a detailed account of parental experiences. According to Cuzzocrea et al. (2016), raising a child with a disability is an enormous responsibility for parents and as ‘childhood disabilities impact parents in significant ways, any information about parental functioning could help us to intervene with these parents more effectively’ (p. 16). This research is particularly interested in parental experiences of raising and educating children with disabilities in a rural context in Nepal. Developing a deep understanding of their experiences, coping strategies and outcomes for all is paramount in being able to develop policies for action that will more effectively support the needs of such families. The following sections review relevant literature on parental stress, challenges, coping strategies and protective factors such as resilience.

2.3.1 Stress and challenges

Literature suggests that in adverse situations most people undergo stages of emotional stress such as disbelief, guilt, rejection, anger, denial and a feeling of helplessness (Al-Farsi, Al-Farsi, Al-Sharbati, & Al-Adawi, 2016; Corr, 1993; Jack, 2016; Kübler-Ross, 1969/2003; Sajjad, 2011). Similarly challenges they face comprise uncertainty, disturbed daily routines, financial stress, health stress, sibling rivalry and recurring despair (Bryant, 2014; Jackson, 2004; Worthington, 1994).

Qualitative research by Jack (2016) in the context of New Zealand reported that parents of children having a particular type of disability (Asperger syndrome) faced the multiple challenges of dealing with their child's anger, anxiety, fear, worry, depression and their inflexible, unreasonable and unpredictable behaviour. Jack (2016) identified that these children's behaviour and social skills, lack of acceptance and stigma, the long medical diagnostic process, inadequate support at school, and family dynamics resulted in increased tension for the parents. Similarly, according to Agyekum (2018), the challenges faced by Ghanaian parents of children with autism include 'the inability of the parents to have meaningful conversations with their children', financial burden, stigmatisation, and 'the demandingness of the autistic children' (p. 166).

Noelle Cauda-Laufer (2017) offers an extensive account of stress experienced by parents of children with disabilities in the USA, which includes financial stress (increased medical costs, socioeconomic disparities, negative effect on employment, need for part-time employment), family-related stress (effect on marriage, effect on siblings, effect on grandparents), and health and wellbeing related stress (social isolation and stigma, lack of social support). Cauda-Laufer also reported that parents felt 'socially isolated, financially stressed, and emotionally taxed when raising a child with a disability' (p. 78).

Bawalsah (2016) in a Jordanian study reported that parents of children with disabilities experience high levels of stress; however, he noted that stress levels varied based on the type and category (severity) of the disability. For example, this researcher found that the stress level experienced by the parents of children with physical disability was higher than parents of children with hearing impairment. Similarly, studies from India and Pakistan report similar experiences of parental stress that depends on the severity of their children's disabilities, age of the child, behavioural issues of the child, and supports and services available to them (Azeem et al., 2013; Desai, Divan, Wertz, & Patel, 2012; Gupta & Kaur, 2010; Upadhyaya & Havalappanavar, 2008).

Research from both developed and developing worlds concurs in many respects in that parents and families experience stress and challenges living with their children with disabilities, irrespective of the type or category of disability. Moreover, studies reveal that these parents do not only experience stresses, challenges and difficulties in their journey of raising their child, they also undergo repeated cycles of grief throughout their journey, for example, when coming to understand the implications of the disability and possible causes, in searching for a 'cure' and in seeking therapy and educational opportunities for their child (Gill & Liamputtong, 2013; Jack, 2016).

Models have been developed that explain the challenges faced by parents and the influence this has on family functioning. For example, the ABC-X model,[8] propounded by Reuben Hill (1949), has been used to analyse stress and coping within families by studying the relationships between different variables such as sources of stress, resources, supports and outcomes pertinent to parental stress and grief. Similarly, there are linear models such as the five-stage model of Kübler-Ross (1969/2003), which comprises denial, anger, bargaining, depression and acceptance. However, linear models may not be relevant to explain stress caused by disability (Worthington, 1994). While grief or stress represented by a linear model is associated with loss or death experiences that often occur once or twice in life and can fade away, grief associated with parenting of children with disabilities is reiterative and cyclic (Boushey, 2001; Ferguson, 2002; Worthington, 1994). Therefore, parents may find some of the stages in the linear model, such as denial, anger, bargaining and depression, blurring in their parenting journey. While there may be an early commencement of the acceptance stage, grief continues to reoccur because of the long-term care need for children with disabilities and the many transition points in life, including entry to school, high school and transition from school to adult life. Ongoing grief is often referred to as chronic grief and, while it may not preclude a person from functioning well in daily life, is never far from the surface (Kurtzer-White & Luterman, 2003; Luterman, 2017; Seligman & Darling, 2007).

Along with stress and challenges, parents and families of children with disabilities have been reported to have rewarding experiences in their parenting journey (Brown, Westbrook, & Challagalla, 2005; Cauda-Laufer, 2017; Gupta & Singhal, 2004; Hodapp, Ly, Fidler, & Ricci, 2001; Lodewyks, 2009, 2015; Swain & French, 2000). Swain and French (2000) identify that a non-tragic or affirmative view of disability 'enhance[s] life or provide a lifestyle of equal satisfaction and worth' (p. 570). Lodewyks (2015) in her study in Canada found that 'parents experience pride, joy and strengthened relationships' while raising a child with a disability and that this experience also

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[8] In the ABC-X model, A denotes the stressor event, B the resources available to a family, C the family's perceptions of the stressor, and X the outcome, either negative or positive (Cuzzocrea et al., 2016; Rosino, 2016).

‘provides them opportunities for personal growth’ (pp. 1–2). Similarly, in Gutman’s research in Israel, parents of children with visual impairment experienced several moments of pride and joy. They felt pride when their children learnt new vocabulary, and acquired unique and important skills such as becoming confident speakers and advocates of disability rights. Mothers in the same research found ‘luxury’ when they received a disability allowance which helped them become ‘stay-at-home moms’ (Gutman, 2007, p. 13). These parents also appreciated the ‘unique aspects of the parent–child relationship’ when they had an ‘opportunity to spend a considerable amount of time at home’ (p. 13). Similarly, in Cauda-Laufer’s (2017) study, parents felt rewarded when they learned ‘how to understand and help their child thrive, to cherish the little things and about unconditional love’ (p. 78). Indian researchers Gupta and Singhal (2004) argue that ‘positive perceptions play a central role in the coping process and assist us in dealing with the traumatic and stressful events’ (p. 31). They also warn that, as ‘negativity in published research’ contributes to negative feelings about disabilities in parents, to help families develop a positive outlook, research should focus on ‘giving space and opportunity to give positive response’ and exploring options for the positive adaptations of parents (p. 32).

2.3.2 Resilience and coping strategies

According to Jack (2016), parents seek strategies to increase their aptitude, resources and coping skills in their quest to deal more effectively with predicaments created by adverse situations. Capacities and resources help parents acquire resiliency, which assists them to face ‘adversity and persistent stressors’ as well as any ‘future challenges’ (Jack, 2016, p. 39). According to Jack (2016), resilient individuals demonstrate the ability to become autonomous; they can mobilise help by actively choosing or creating situations that ‘complement their approach to life and promote their strengths’ (p. 39). However, the literature indicates that this is only possible if parents are not feeling overwhelmed and are supported in exploring their strengths and assisted by high quality services and resources. Parents bring individual dispositions to face unexpected challenges and as such what is suitable for one person may not always work for another (Sajjad, 2011; Singal, 2016a; Turnbull et al., 2013). For example, some families may draw on religious beliefs and faith while others seek more tangible support for coping with their children’s disabilities. In the context of Nepal, it is not surprising to find parents referring to religious and spiritual beliefs as a resource for coping.

In Nepal, parents’ belief in the doctrine of *karma* is reported as a major strategy to deal with suffering (Whitman, 2007). Religious-cultural views about disability in Nepal are deeply rooted in the age-old Hindu belief system that attributes disability to one’s *karma* (actions) or, more precisely, disability is seen as the result of inappropriate actions that are not in line with the *Dharma* – the law of nature. Such actions from a previous life/lives or even from this life can result in tragedy (Whitman, 2007). In his popular book *Fatalism and development: Nepal's struggle for modernization*, Nepali anthropologist Dor Bahadur Bista characterises Nepalese society as having a fatalistic worldview (Bista, 1991). Bista's proposition is supported by the results of UNICEF et al.'s (2001) research which found about one third of Nepali people believe in a metaphysical cause for disability. Such beliefs may be supportive of more effective coping and therefore this area will be explored in this current research.

Religious/spiritual beliefs and practices, as strategies for coping with challenging situations, have been important resources used by societies across the globe. For example, the doctrine of *karma* in Hindu-dominant societies including Nepal influences people to make sense of their grief and devise coping strategies. Studies have reported that families and parents demonstrate their resiliency with the help of worship, vows and pilgrimages to religious sites such as temples. Such beliefs enable people to accept and emerge from tragic life events. Anand (2009), through his narrative study about how Indian women make sense of their suffering and cope with their reality, also showed that *karma*, as a widely accepted doctrine in the Hindu population, provides an explanation for various life crises. It gives more motivation to parents living with suffering to become strong and accept challenges, despite those challenges initially being perceived as 'persistent, pervasive, cumulative and unpredictable' (Jack, 2016, p. 145).

Sajjad's (2011) research from Pakistan echoes a similar view on religious belief, reporting that, even though each individual may have different feelings, approaches and management strategies about disability, religious background influences individuals' perceptions about disability. In Africa also, as reported by Agyekum (2018), Ghanaian parents cope more effectively by adopting strategies like 'depending on God for strength' in addition to seeking medical care, receiving support and encouragement from others, connecting with support groups and taking leave to help their child (p. 166).

Nevertheless, both religious and non-religious ways of dealing with disability are discussed by various scholars. Bawalsah (2016), in research situated in Jordan, describes two types of coping strategies: emotion-focused (religious) and problem-focused strategies. Emotion-focused coping draws on religious practices, praying, expressing feelings, yoga and meditation to alleviate parental stress. Problem-focused coping strategies refers to families' involvement in productive activities, such as advocacy, mobility and social participation. The research also found that some parents used disengagement as a coping strategy, indicating they do not actively use any strategies to overcome the stress; rather they engage in avoidance of thinking about problems. Turnbull (1993) (see also

Turnbull et al., 2000) notes that fathers, compared to mothers, would often disengage and spent more time at work to avoid the challenges of parenting their child with a disability.

In research from Italy, Cuzzocrea et al. (2016) describe two types of coping strategies, 'internal and external' (p. 4), adopted by parents. While internal coping strategies relate to parental perceptions or beliefs about disability, external strategies are linked with support available from the outside. The internal and external copying strategies resemble what Bawalsah (2016) calls emotion-focused and problem-focused strategies. Similarly, Cauda-Laufer (2017) discusses behavioural and resource-led coping strategies to describe similar types of strategies.

Cuzzocrea et al. (2016) further argue that, with a decrease in parental hopes for recovery as their child grows, they tend to seek the second kind of coping strategy, namely resource-led strategies or support from the outside. They refer to various other research in identifying the importance of multiple dimensions of social support. For example, spousal support, marital satisfaction and support from friends are reported to help reduce parenting stress levels and assist family functioning (Turnbull et al., 2013). Social support is considered an important resource in Sajjad's research from Pakistan as it relieves stress and sorrows, improves health, increases resilience, 'multiplies joy, and softens sorrow' (Sajjad, 2011, p. 76). The presence of others is important for these parents to relieve their stress because parents can confide their sorrows and seek help and support (Sajjad, 2011). However, according to Cuzzocrea et al. (2016), the availability of professional support and services is not necessarily found to be helpful in reducing parenting stress. Some professionals and services do not cater for the specific needs of the family and 'can therefore be experienced by parents as an additional source of stress' (p. 5).

Other studies discuss adaptive strategies and maladaptive strategies in dealing with stress and challenges (Brown et al., 2005; Roming, 2018). While adaptive coping strategies include positive behaviours such as exercise, religious/spiritual practice, and seeking social support, maladaptive coping strategies that include smoking, alcohol and substance use, or unhealthy eating are often negative in their consequences (Roming, 2018). According to Quian (2012), parents who use more maladaptive coping strategies are likely to 'experience more symptoms of depression, anxiety, and hostility' (p. 5).

Moreover, studies reveal that in most cases parents rely on their own resources, given the lack of external and professional support available to them. Jack (2016) found that most parents in his research in New Zealand managed challenges using internal resources such as 'meaning making, developing resources, planning ahead and solving problems; and strengthening intrapersonal assets'

(p. 68). However, he underscores the need for external support for successful and sustainable management of such challenges. The lack of external supports and insufficient resources for the parents of children with disabilities in South Asian countries are noted to have negatively impacted parental resilience, as highlighted by Singal's (2016b) study in India, Sajjad's (2011) study in Pakistan and Shah Thapa's (2012) and Barriga's (2011) studies in Nepal.

In summary, various conditions such as socioeconomic resources, culture, finances, type and severity of disability, attitudes, support and services available affect how parents and families cope with the stress of parenting children with disabilities. Coping strategies are important for parents given their struggle to manage the overwhelming experiences of parenting. External supports, however, are needed and should be tailored to address the stress, challenges and the specific needs of individual parents and families, noting that their needs will change over time as well (Turnbull et al., 2013).

2.3.3 School choice and educating experiences

Parental choice about enrolling their children with disabilities in schools depends on the values, beliefs and attitudes they hold towards education. These decisions are often shaped by parents' cultural and educational backgrounds, aspirations for their child's future and/or social class (Hornby, 2015; McCarthy, 2016; Poet, Wilkinson, & Sharp, 2011; Rogers, 2007; Rose, 2018b). In general, in western contexts the choice of a particular school, according to McCarthy (2016), depends on the academic status and social reputation of the school as perceived by parents. Parents tend to relate academic status with future careers or post-school degrees and social reputation refers to the schools' extra- or co-curricular practices that inculcate values, life skills and independence in students (McCarthy, 2016). In developed countries, parents know schools' academic status through school ranking lists which are publicly available and social reputation through testimonials, word of mouth and direct observation of schools. However, the parents of children with disabilities even in developed contexts may not have enough choices of schooling for their children with disabilities due to limited schooling options (Hornby 2015; McCarthy, 2016; Rogers, 2007).

The decision-making patterns of parents in choosing special or mainstream schools for their children with disabilities are not predictable. According to Hornby (2015), in New Zealand or the UK, some parents have a preference for inclusive education while others may prefer special schools (Hornby, 2015). Factors like children's acceptance by their peers or academic achievement are considered as predictors of those decisions. Poet et al. (2011) mention a number of factors that influence the decision making of parents in the UK: 'ability to meet their child's needs; availability of specialist care; availability of experienced and qualified staff; location (distance from home); the ethos and atmosphere; size of classes and school; opportunity for the development of independent living skills' (p. 9). Parents in their research preferred residential schools because these schools support students with disabilities to become independent, have medical expertise and specialised support resources, and provide opportunities for personalised learning. However, these findings may also reflect the cultural practice of residential schools being the traditional option for the education of children with disabilities in the UK.

Hooja (2009) noted that Indian parents prefer special schools because these schools provide 'a caring and supportive environment'; and they 'did not want to risk an uncertain welcome in mainstream schools' (p. 354). However, after many years of sending their children to mainstream schools, parents have started to become positive towards mainstream schools. In this regard, Rogers (2007), a scholar from the UK, points out that if parents had to choose between mainstream and special education, then they would choose a mainstream school because it is part of the 'real' world, unlike special schools which are like a 'cotton wool' world (p. 112). Hooja, Rogers and Hornby's research suggests that parents' experiences and insights are important contributors to their choice of a schooling option for their children.

There appears to be no research on what influences parental choice in selecting a school for their children with disabilities in Nepal. Integrated schools in Nepal are sparsely located and hence are often a significant distance from the homes of many parents. As parents do not have other schooling options for their children with disabilities, integrated schools with residential facilities are often the only choice for them. Moreover, in Nepal, there is a lack of research evidence about whether or not they are happy with residential provisions or whether parents would select a non-residential school if it was an option. This current research will invite parents to comment on aspects of their decision on schooling options for their child.

2.4 Parental engagement

In this section, international and national research is reviewed to generate an understanding of parental engagement in the context of special needs education. The section also offers a historical account of and research related to parental engagement in Nepal. Then the determinants (enablers and barriers) of parental engagement, theoretical models and practical strategies for encouraging parental engagement as identified in the literature are discussed.

2.4.1 Different uses of terms: Participation, involvement and engagement

Terms such as parental participation, involvement and engagement are commonly and sometimes synonymously used to refer to a school's collaboration with parents. Similar terms such as 'home–

school', 'family–school', 'parent–teacher', 'parent–professional' partnership, cooperation or teamwork are also used synonymously across the literature to refer to the same phenomenon (Beveridge, 2005; Hoover-Dempsey & Sandler, 2005; Hornby, 2011; Turnbull et al., 2013). However, many writers are cautious about the differential use of terminology as they perceive that each term can have a different meaning, intent and scope (Constable, 1994; Ginanto, 2018; Goodall & Montgomery, 2014; Pushor & Ruitenberg, 2005; Smit, Driessen, Sluiter, & Sleegers, 2007). Constable (1994), for example, distinguishes between the terms 'participation' and 'involvement':

> Participation was to include the practical activities in which individuals took part such as making a response to a questionnaire, writing a document or organizing a working party or being a member of one, whereas involvement was a positive feeling associated or not with any of these activities. (p. 92)

This indicates that involvement can create in people a greater sense of belonging to the projects with which they are associated. According to Ginanto (2018) parental involvement indicates a stronger commitment than participation because involvement calls for parents to actively reach out to schools and schools to actively invite parents to be involved with them.

Other writers differentiate between 'involvement' and 'engagement'. Parents' roles and tasks in their involvement are largely given or defined by rules, regulations or professionals. However, parents' roles and tasks may evolve naturally when they are truly engaged in their child's education. Pushor and Ruitenberg (2005) state: 'The person "involved" is co-opted, brought into the act by another party. … The person "engaged" is an integral and essential part of a process, brought into the act because of care and commitment' (pp. 12–13). For them, 'engagement' encourages parents to take their place alongside the educators in children's schooling, while 'involvement' only infers that parents do those things that school professionals ask them to do (Goodall & Montgomery, 2014). However, since above studies reflect the western context, such concepts may not reflect the Nepali context and practices where parents often have less engagement even in mainstream schooling.

In Nepal, words such as *sahabhagita, sahakarya, sajhedari or bhagidari* can be used interchangeably to capture the English words participation, involvement or engagement. A literature search did not yield any research from Nepal that explains the subtlety of the use of these words. Although the current practices in Nepal of parent–school relationships might be characterised as evolving from 'participation' and someway moving towards 'involvement', its ultimate aim should be to achieve quality 'engagement' of parents. To appreciate the values inherent in the concept of 'engagement' and the outcomes anticipated from this, the word engagement is preferred in this research.

However, ‘engagement’ is not used consistently because not all literature referenced in this research has treated these terms with such subtlety.

2.4.2 Parental engagement in special needs education

Engagement of grassroots people in general is considered important for the development of any sector, including education, because through such participation people can develop their capacity, build a sense of ownership and make development efforts sustainable (Chambers, 1983; Kothari, 2001; see also Cooke & Kothari, 2001; Yates, Carrington, Gillett-Swan, & Pillay, 2019 on special needs education specifically). In this light, parental engagement in school activities is crucial for the success of students and their school’s performance (Burke, 2012; Collier, Keefe, & Hirrel, 2015; Cologon, 2013; Forlin, 2013; UNESCO, 1994, 2006; Yssel et al., 2007). The arguments are equally applicable to the case of special or inclusive education (Beveridge, 2005; Hornby, 2011; Singal, 2016a; UNESCO, 1994).

According to Fox and Olsen (2014), ‘Parental engagement involves partnerships between parents and schools, that children’s learning is a responsibility shared by both parties, and that parents and teachers play different but important roles in children’s learning’ (p. 20). Burke (2012) states that parental engagement in inclusive education could help schools impart appropriate services for children’s needs. Similarly, many studies assert that, without engaging parents and families, any real progression towards special needs education is impossible (Alur & Timmons, 2009; Beveridge, 2005).

Carrington and Robinson (2006) emphasise the principle of valuing and collaborating with ‘parents and the broader community’ ‘to meet the needs of diverse learners within an inclusive school culture … [and] to support the development of a more inclusive school community’ (p. 326). Mitchell (2015) adds: ‘Children will obtain positive messages about the importance of their education if they see their parents and educators working together’ (p. 339). It not only helps boost school successes but also psychologically supports students, parents and teachers (Rosner, 2014; Hoover-Dempsey & Sandler, 2005). In the West, research indicates that parental engagement has been considered essential to the success of special needs education (Beveridge, 2005; Carrington & Robinson, 2006; Dale, 2008; Porter, 2002).

In Australia, Forlin et al. (2013) note: ‘The involvement of the family is an important and essential element [and] … true home–school collaboration is necessary for success’ (p. 19). They considered parental involvement as an important parameter in reviewing inclusive education in seven countries: Australia, Canada, the UK, Italy, Cook Islands, Finland and the Ukraine, and reported that most of these nations articulate the importance and necessity of parental engagement in policies. For example, in Australia and Canada, 'Parents are supposed to be active partners in their child's education' (Forlin et al., 2013, p. 57).

In the UK, a number of reports and policies highlight parental engagement in the schooling of children with disabilities, such as the *Warnock Report* 1978; the White Paper *Excellence in Schools* 1997; the White Paper *Higher Standards, Better Schools for All* 2005; *Every Parent Matters* 2007; and the *Engaging Parents in Raising Achievement Initiative* 2007 (Barlow & Humphrey, 2012). Thus, parental engagement has been at the core of special needs education from as early as 1978 when the Warnock Report was released, as this report paved the way for 'partnership with parents and a number of measures were put in place to try to ensure that this happened in practice' (Harris, Riddell, & Smith, 2008, p. 9). However, it does not mean that the country has achieved all anticipated outcomes of parent engagement, as several issues remain.

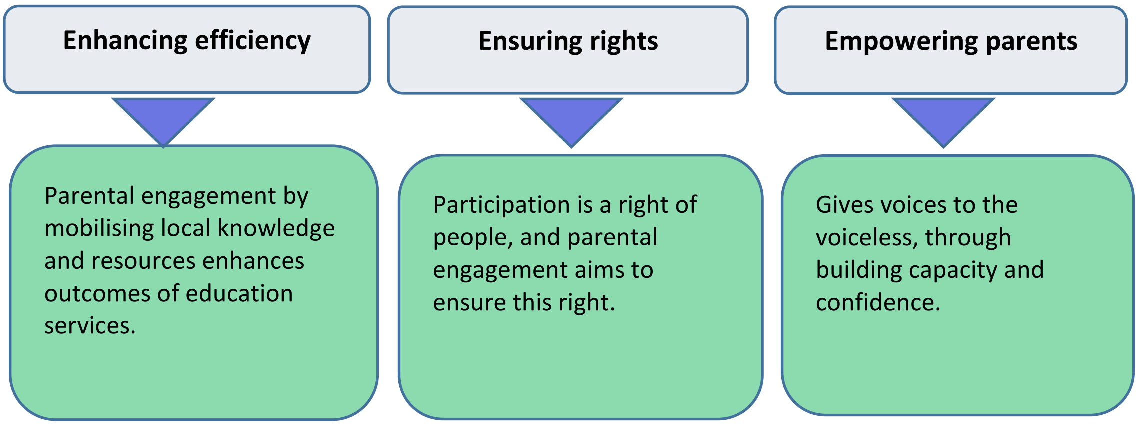
Similarly, in the USA, parents are considered the most powerful contributors in special needs education. For example, 'it is mandatory for parents to be involved in the development of Individual Education Plans and they have due process rights to enforce such plans' (Mitchell, 2015, p. 338). The Individual Education Plan (IEP) is a legal document in the USA. Although not carrying the same legal weight elsewhere, IEPs are widely used in other developed nations including the UK, New Zealand, Republic of Ireland, Canada and Australia to formally invite parents to engage in setting the educational goals for their children with disabilities (Kearney & Kane, 2006; Keen, 2007; Loreman, 2014; Morton, 2012; Rose, Shevlin, Winter, O'Raw, & Zhao, 2012; Selvaraj, 2015; Slee, 2005, 2007). However, their engagement in the IEP processes in these countries does not necessarily reflect quality parent engagement in their child's schooling. This could be because IEP meetings are usually only held once or twice a year; while quality parent engagement involves sustained and regular involvement in decision making (Goepel, 2009; Morton, 2012; Turnbull et al., 2013).

While in the West, parents 'have been the driving force behind the movement to include children with disabilities in mainstream education' and the 'parental lobby' has achieved change in schooling options (Wong et al., 2015, p. 85; see also Altieri, 2001; Bissaker, 2015), this has not been the case in developing countries (Hooja, 2009). In developing countries, however, academics and policy makers are increasingly recognising the importance of engagement of parents including local communities in the education of children with disabilities (Afolabi, 2014; Mitchell & Desai, 2005). Afolabi (2014), in a study in Botswana, for example, finds parental engagement as a positive strategy emphasised by not only researchers, but by policy makers in that they widely recognise the need to incorporate parent voices in policies. Studies from the South Asian region, similarly, emphasise parental voices as important in the success of educating children with disabilities, although parental engagement is not always evident in practice. For example, Singal (2016b) in a study conducted in India found that the ‘policy discourse continues to overlook the potential of working with parents as partners’ (p. 39). She calls for an environment where schools and families work together so that children can realise their full potential. Personal observation would suggest parent lobbying for greater schooling options in Nepal is also very limited.

UNESCO’s (1994) Salamanca Statement proved to be a significant reference point, or a prime mover to persuade member countries and mobilise the global community to value increased parental engagement in special needs education (Rose, 2018b; Mitchell, 2005). However, Mitchell asserts that, ‘while many countries seem committed to inclusive education in their rhetoric, and even in their legislation and policies, practices often fall short’ (2005, p. 11). Therefore, the gap between the intent of the statement and the practical reality has been found to be significant even in developed nations, let alone in developing nations.

2.4.3 Goals/focus of parental engagement

Parental engagement is designed to achieve several objectives. As summarised from the research, the three key goals to be attained by parental engagement are enhancing efficiency, ensuring rights to participation, and empowering parents. Figure 2.2 depicts these goals and they will be explored in more detail in the following sections.



Parental engagement by mobilising local knowledge and resources enhances outcomes of education services.

Participation is a right of people, and parental engagement aims to ensure this right.

Gives voices to the voiceless, through building capacity and confidence.

Figure 2.2: Goals/focus of parental engagement

Enhancing efficiency

The efficiency objective proposes that parental engagement contributes to students’ higher achievement, regular attendance, decreased drop-out rate, more positive attitudes and behaviours, higher graduation rates, and parents’ good relationships with teachers and schools (Emerson et al., 2012). Lewis and Naidoo (2004) argue that parental engagement helps maximise children's and schools' successes with minimal investment and inputs. According to Emerson et al. (2012), 'parental engagement returns positive financial benefits to the nation' (p. 50), by raising the quality of education, which eventually contributes to the productivity of the nation. This goal of parental engagement seems to be linked to neo-liberal thought in that 'efficient allocation of resources is the most important purpose' of any management. Neo-liberalism prefers interventions which maximise output without raising costs (Thorsen & Lie, 2006, p. 8). Neo-liberal thinking, an output-focused orientation in development, which originated in the UK with the advent of Thatcherism and was propagated by the World Bank, calls for more liberty for the private sector (Thorsen & Lie, 2006; see also Morton, 2014). It seeks high efficiency or a high input–output ratio so that the associated costs of any program can be reduced. It therefore calls for policies in the education sector that stress 'marketisation, privatisation, competition, choice and decentralisation' (Thapaliya, 2018, p. 8). These neo-liberal motives are clearly reflected in Nepali education policies of 1990s and beyond; the transfer of fiscal and management responsibilities to local school management committees (SMCs) is one such example (Bhatta, 2011).

Community or parental engagement was one of the measures proposed to enhance efficiency and reduce educational costs in developing countries like Nepal. In that sense, the efficiency goal of parental engagement may be a narrow view as it could be perceived as just a tool to serve technocratic ends, which suggests parents in this case learn their roles to align with official procedures or to master technical skills (Lewis & Naidoo, 2004). Lewis and Naidoo (2004) argue that the intent behind the invitation for parents to engage in school processes may be limited to achieve 'efficiency' in terms of cost and product, rather than empowering people (Lewis & Naidoo, 2004; see also Beveridge, 2005).

Ensuring rights

Participatory development sees the rights, power and wisdom in ordinary people and therefore seeks their active involvement in the decision-making stages of any type of developmental work (Lewis & Naidoo, 2004). Pioneered by Paulo Freire, Robert Chambers, Uma Kothari and others, participatory development holds a strong promise for developing any section of a society, including special needs education (Cooke & Kothari, 2001; see also Chambers, 2014). Underpinned by post-modern thinking, this school of thought recognises local wisdom and realities as important resources for development efforts (Cooke & Kothari, 2001; Pokhrel, 2004), which can be harnessed by giving voices to lay people or ensuring their rights to participate in the process.

The argument for this objective has its roots in the early 1960s movement known as the social justice movement, when voices of women and racial minorities were brought to the fore (Charlton, 1998). The movement succeeded in achieving several changes including voting and representation rights for women and marginalised races in different continents through legal reforms such as the right to vote for African Americans in 1965 in the USA and voting rights for women in the 1960s in many countries of the African continent. Similarly, according to Charlton (1998), the disability movement emerged about the same time, which conveyed a strong message that people with disabilities 'know what is best for themselves and their community' (p. 4), and the movement also reinforced the slogan 'nothing about us without us' (p. 17). Similarly, as per parents' demand, they were viewed as having rights to be engaged as full, equal and valued partners of schools in every decision that influences their child (Beveridge, 2005; Ong-Dean, 2009), and such an invitation to parents helps ensure their fundamental right to participation (Ong-Dean, 2009).

Empowering parents

Parental engagement should encourage parents to build confidence in school processes, for which empowerment is crucial. According to Lewis and Naidoo (2004) and Charlton (1998), proponents of empowerment believe in transformation and intend to give parents real power; empowerment therefore challenges the status quo[9] and liberates people from oppression. Parental engagement helps build parents' capacity and confidence so that they feel empowered (Byrne, 2001; Dudley, 2017; Lewis & Naidoo, 2004; see also Beveridge, 2005; Bissaker, 2015). This goal's focus is more on the process, rather than the product. According to Turnbull et al. (2013), to meet this objective, however, is not an easy task as it requires all principles of partnership (equality, reciprocity of ideas, trust, respect, professionals' confidence in parents' wisdom, capacity, action and judgement) to be followed genuinely. When empowerment becomes the objective of partnerships, parents are regarded as equal partners and are likely to be provided with a number of means and interventions to meet their needs. According to Bissaker (2015), in its most advanced form empowerment leads to the enablement of the people involved, which may require the supply of 'the means, knowledge, or opportunity to be or do something' (p. 8).

Although this section has drawn mainly on western literature, these goals and propositions seem to be equally important for Nepal, in the context of the efficiency motives influenced by neo-liberalism

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[9] Status quo is Latin for 'existing state'. Status quo generally connates a negative meaning. If a person wishes to maintain the status quo, then he/she is considered resistant to progress.

in Nepali educational policies (Thapaliya, 2018), the rise of rights-based initiatives (Acharya, 2007), and people's aspirations towards greater inclusion and empowerment (SCA, 2015).

2.4.4 A historical account of parental engagement in Nepal

In mediaeval times in Nepal (until the 18th century), parents themselves (mostly fathers) were supposed to be the gurus or teachers of their children (mostly sons) (Sharma, 1993; Valentin, 2005; Shah, 1992). However, during the Malla Dynasty (1274–1769), some parents also sent their children to teachers' (mainly Brahmin gurus') homes in the quest for education (Sharma, 1993). In those times, religious institutions (such as Hindu *Gurukul*s and Buddhist *Bihars*) provided education to only selected sects of the societies. In most cases, students were the boys of *Brahmins* (priests), *Chhetri*s (soldiers), *Vaishyas* (businesspeople or artisans) and those from noble families, suggesting that girls and children of *Shudras* had little chance of accessing an education. Education was free at that time. Although 'imparting education to the public was not considered to be one of the main functions of the State, there was no dearth of educated people in Nepal' (Shrestha & Singh, 1972, p. 78).

Later when a rudimentary concept of schooling (a group of children to be gathered in a particular place and facilitated by a more learned person to help them acquire education) emerged, parents and communities started to invite educated persons to their localities to teach their children. They would arrange food and shelter for the teachers, as they often came from a distant place. Therefore, parental and community engagement in education 'has been existent from the beginning of the Nepalese educational history' (CERID, 2009, p. 11).

Only in 1853, then Rana Prime Minister established the first formal school, the Durbar (or Palace) School. However, as the name suggests, the school was only for the children of ruling class families. Only after some 30 years was the school opened to the public. There was not much expansion of the public education system until the 1950s, as evidenced by the literacy rate of the country, which was only 2 per cent in 1950 (Sharma, 1993; Khanal, 2013; Shrestha & Singh, 1972). With the advent of a democratic system in the country in 1950, the public-school system began to expand through government efforts (Khanal, 2013). Management of education was primarily the concern of parents and communities until 1950 and in fact continued to be so until the early 1970s. Especially with the implementation of the National Education System Plan (NESP) in Nepal in the early 1970s, the state took more responsibility for education with an aim to nationalise the system, with a nationwide uniform curriculum structure, and teachers' supply, qualification, training and pay scales (Khanal, 2013; Sharma, 2008). Unfortunately, this action of the government became detrimental to parental engagement in public education as it minimised parent and community roles. With the increasing role of the state, parents became less involved, because the traditional roles of parents and communities in school management, such as management of land, building and teacher, were not recognised by the government's new initiative, the NESP.

In the 1980s, people's participation through political decentralisation was initiated with Nepal's first *Decentralisation Act 1982* (His Majesty's Government of Nepal [HMGN], 1982). The education sector responded to this decentralisation by amending the existing *Education Act* and allowing some representation of parents in school management committees (SMCs). However, this reform, according to Dhungel, Sapkota, Haug and Regmi (2011), was not decentralisation in a true sense, as true decentralisation promises the transfer of power to local communities. Rather it was just a devolution of power from central levels of government to their own people at the district level. Dhungel et al. (2011) opine that the term decentralisation should not only focus on 'the powers, functions and duties of formally established local bodies' (p. 28), but it should also capture the roles of communities and local institutions and their linkage with local bodies. Such is not the case, however, when the district-level bodies of government selected only parents who supported government interests to join the SMCs. Hidden in such an action was the political interest of the then ruling class regime, the so-called Partyless Panchayat System, led by the then active monarch.

After the 1990s, the government officially recognised the essential role of the community in education, although, as described above, communities in Nepal to some degree were always active in school affairs. This change in the educational governance system was in line with the spirit of the people's movement of 1990, which had overthrown active monarchism and reinstated the multiparty democratic system. The 1990s movement highlighted the concerns of marginalised sections of the populace such as *Janjatis*, *Dalits*, *Madhesis* and women, and their aspirations to inclusion and participation in every sphere of social lives (Tamang, 2017). In 2002, a more prominent step towards parental involvement was undertaken through the seventh amendment of the *Education Act* (NLC, 2002). A milestone in the education decentralisation effort, this Act entrusted various powers to parents and communities. Parents started to have a significant role in the formation of the main decision-making body of the school, the SMC. Parents could choose four members from among themselves (including the chairperson) to be part of the 10-member SMC. They adopted democratic processes to choose these representatives. In addition, a strict definition of 'parent' was employed, which included father, mother, grandfather, grandmother and elder siblings, so that any interference from false representation could be controlled (NLC, 2010). Two members of the SMC came from ex-officio positions – the school head teacher and the ward representative of the relevant village council served as the member-secretary and as a member respectively. One member represented teachers. The SMC nominated the remaining three members from donors, educationists and patrons or founding members of the school. The power entrusted to the SMC included recruiting teachers and mobilising them; preparing the school improvement plan; and allocating and spending funds, generated on their own and received from the government, according to their priorities (Bista & Carney, 2004; NLC, 2002).

Both pushing (donors' conditions) and pulling (demands from parents) factors enabled the above-mentioned positive developments to occur. The continuous pressure from external donors in the spirit of neo-liberal thinking and the pressure from internal stakeholders contributed to the Nepalese government giving more powers to communities and parents (Bista & Carney, 2004). In sum, the call for parents' engagement in policies came as a response to demands to make education more relevant to local needs, to enable parents to have more control over school affairs as well as to get the most from the resources invested in the education sector guided by conditions of donor agencies influenced by neo-liberal policies; however, their implementation raised several questions. While these changes and concerns were visible in the mainstream school context, they did not affect the system that governed special needs education. What follows here is an account of recent research studies undertaken in Nepal in regard to parental engagement in both mainstream and special needs education contexts.

2.4.5 Research on parental engagement in Nepal

Although parental engagement in school affairs has been a key agenda of education reform in Nepal (MoES, 2001, 2003, 2004; MoE, 2009, 2015; NLC, 2010), research that explains the aspects, types, nature, opportunities, paradoxes, dilemmas, difficulties and barriers related to parental engagement especially in the context of special needs education in Nepal is sparse. However, some studies have been undertaken to explore the issue of community and parent engagement in mainstream school contexts (Bista & Carney, 2004; Carney, 2008; Carney, Bista, & Agergaard, 2007; Khanal, 2010, 2013; Sharma, 2008; Tripathi, 2008). In addition, although not focused on parental engagement, a number of researchers have studied the general aspects of special needs education (Acharya, 2007; Barriga, 2011; CERID, 2004, 2006, 2008; Kafle, 2002; Lamichhane, 2013, 2015; Plan, 2014; Regmi, 2017; Shah Thapa, 2013; UNICEF et al., 2001).

Sharma's (2008) study in the mainstream education context takes up parent and community involvement issues from a rights-based position. He maintains:

> The shift to increase community control of schools can be seen as a move to enhance and reframe democratic right and participation. Instead of top-down administrative decision-

> making, a broader base of constituents should be included in shared educational decision-making. (p. 73)

For this, Sharma argues, schools should not demand more from parents and communities; rather they need to think how they can be an integral part of schools. He warns that reforms to empower parents may offer new and unpredictable challenges for educators, which they should manage courageously.

Dhungel (2004) and Dhungel et al. (2011) view parental engagement from a governance perspective. For them, engagement is a key to democracy. According to this perspective, the government or any public institute cannot claim legitimacy unless they ensure citizen's engagement. Decentralisation brings government closer to people. It should allow citizens' representation and engagement in the different stages of development programs including planning, implementation and evaluation (Dhungel et al., 2011). This perspective puts local people in the position of planner or manager of development programs. Citizen engagement should become 'an integral element in local, regional and national development plans and programmes for economic growth, social equity and regional balance' (UN, as cited in Dhungel et al., 2011, p. 29). This line of thought argues that parental engagement is necessary to bring local communities closer to schools (state mechanisms) to reinforce the state's legitimacy and gain public confidence. However, according to Edwards (2011), 'government efforts to decentralise education fail to engage and involve community-level stakeholders, particularly parents' in Nepal (p. 77).

The main argument behind this focus on citizen's engagement was that decentralisation could not function well in the absence of people's engagement; as people's engagement is the heart, head and hand of decentralisation and development (Dhungel, 2004; Dhungel et al., 2011). People's engagement in the developmental effort is continually advocated by international agencies such as the United Nations, which often insist that member states make every developmental effort participatory. Nepal's decentralisation agenda was a response to the international agenda, but it has not been widely implemented in practice.

Carney and Bista (2009), Carney (2008) and Carney et al. (2007) have critiqued Nepal's move towards people engagement. To them, neither people engagement nor decentralisation is a panacea. These researchers in the mainstream school context 'found no evidence of a causal relationship between approaches to school management and school improvement' and 'no definitive link between school-based management and student learning' (Carney et al., 2007, p. 616). In addition, they report that parent participation in school affairs is limited to supervisory roles such as checking teacher's absenteeism. In such a situation, teachers oppose school decentralisation initiatives because they believed parents, who are most likely to be illiterate, should not be granted this kind of supervisory role; as they think it undermines their professional self-respect and dignity. Their study reveals that teachers in Nepal think that they should possess more control in schools. Moreover, the prevalent educational governance structure supports the upward accountability of teachers to District Education Officers and School Supervisors, suggesting that schools and teachers are not required to respond to parents or students for their outcomes including schooling results.

Basu Kafle in his PhD dissertation titled *Including the excluded: A critical evaluation of special needs education programme in Nepal* uses parental engagement as one of the parameters to assess the inclusive education practices of Nepal (Kafle, 2002). He found that special needs education in Nepal requires massive improvement to meet its stated objective. He suggests that 'parents [of children with disabilities] should be motivated and encouraged to visit the school with concern about the progress of both their children and school', and schools should take the lead in this matter (p. 299). He also believes that this area is pertinent for future research (Kafle, 2002) with an understanding that increased roles for parents will enhance the outcomes of special needs schools in Nepal.

Similarly, CERID (2004) quotes Tisdell to highlight the need for parental engagement in every activity in schools in Nepal that is 'planned and implemented for the children with disabilities' (p. 8). CERID maintains that parental engagement is required 'if schools are to be made inclusive' (CERID, 2004, p. 12). It reiterates this view by stating that parents' engagement is required 'to make school resourceful' (pp. 68–69). CERID further urges that awareness programs for parents are required to give them necessary information about special needs education. CERID highlights this need for awareness again in its 2008 study also. However, these studies are not informed by parental experiences and insights and my research aims to fill that gap.

Barriga's (2011) qualitative study, undertaken in the far western part of Nepal and commissioned by Human Rights Watch, New York was a substantial study involving parents of children with disabilities. Of a total 97 participants, 23 parents and family members were interviewed. The research found that parents or family members of children with disabilities were unaware of their children's rights and educational options. Despite the opening of 62 assessment centres throughout the country with a major mandate to reach out to parents, Barriga's study found that 'The Nepalese government has not done enough to inform the public about the right to education for children with disabilities' (p. 34). Other issues raised by the study were negative attitudes of parents towards the learning ability of their children, and schools' refusal to admit children with disabilities. To make special needs education effective, the study recommended that schools 'train and support parents of children with disabilities, including through regular parents' meetings', 'consult parents or family members in decision-making and monitoring processes', as well as 'increase their participation in the School Management Committees (SMCs) and Assessment Centres' (p. 9).

Shah Thapa's (2012) study, one of the rare studies in Nepal that focus on girls with disabilities, looked into the perceptions of relevant stakeholders including parents regarding schooling of their daughters with disabilities. The study reports that, while some parents were positive about the education of girls with disabilities and were active in early detection of their children's disability as far as possible, others saw their child as a burden and hid them from the wider community, as they lacked information about services. These findings also concur with Barriga's (2011) study, undertaken in the far western region of Nepal, another study that includes issues of education of girls with disabilities. Barriga's study reports that 'girls with disabilities are often hidden in their homes away from the public and may not be included in any data on children with disabilities' (p. 15). Moreover, according to Barriga, girls who get a chance to be enrolled in schools are likely to drop out before they reach puberty because of the lack of services such as accessible toilets in schools. It is noteworthy that Shah Thapa's study found that girls with disabilities were found to display active agency such as being hard working and showing self-determination to cope with the problem they face in schools. Regarding parents' engagement, she observes that 'parents are compassionate for the care and treatment' (p. 97), but their efforts are vulnerable, given the lack of services related to early detection, treatment and intervention in Nepalese communities.

Lamichhane (2013, 2015), a PhD scholar with visual disability, has studied disability from economic/investment and attitudinal perspectives. He asserts that special needs education increases the likelihood of getting a job, thus reducing the burden on families. He argues that education saves government expenditure in the long run by cutting welfare budgets, as individuals begin to earn their livelihood. He further emphasises that, through education and employment, people with disabilities become more satisfied and less dependent on the family; they are also perceived as exemplary role models in society even for those without a disability. He is also critical of the government as well as parents for investing more in children *without* disabilities.

Regmi (2017), in his recent study, argues for the need for parental engagement for the success of inclusive schools (although it was not within the scope of his study as the aim was to explore the perceptions of teachers about inclusive/special education in Nepal):

> In a truly inclusive school, the principal, teacher, parents and students work collaboratively to ensure that all members of the school community experience a sense of being welcome, of belonging and of being valued within the context of school. (p. 53)

He found a wide gap, what he calls an ‘implementation gap’, between policy provisions and school-level practices. The gap is due to the negative attitudes of teachers and the community towards special needs education. The study views ‘collaboration with the local community as a key strategy to steer the culture of inclusion in schools … in Nepal’ (Regmi, 2017, p. ii).

Thapaliya (2018) in his doctoral study interviewed 14 parents (of the total 48 participants) to explore the understanding and experience of education officers, school administrators, teachers, parents and students with and without disabilities about inclusive education. This study also found a gap between education policies and implementation of inclusive practices; however, the issue that my research highlights – parental engagement in schooling of their children with disabilities – was not the focus of Thapaliya’s study.

Dawadi (2019) in her recent qualitative study identified parental and community engagement as one of the powerful organisational factors along with others (policy, attitudes, teacher efficacy, resources and coordination as organisational factors, and spirituality, caste, ethnicity, language, economic status and geographic location as contextual factors) that influence the early childhood development outcomes of young children with disabilities. As such, policy makers’ and practitioners’ understanding of these factors can contribute to increasing the access of young children with disabilities to early intervention and education programs and support their holistic development.

2.4.6 Determinants of (enablers of and barriers to) parental engagement

In this research, the term ‘determinants’ is used to refer to both enablers and barriers. For example, ‘attitude’ is a determinant, as it can be both an enabler of and a barrier to parental engagement depending on whether it yields a positive or negative impact on parental engagement. Chindanya (2011) also uses the term ‘determinant’ in her study related to parental engagement in the mainstream education context of Zimbabwe, although many other studies use the terms enablers and barriers, or their equivalents, separately.

A range of interacting factors determine the level and quality of parental engagement and their relationships with teachers and professionals. A review of the literature revealed various determinants of parental engagement in the context of special needs education (Barriga, 2011; Beveridge, 2005; Burrows, 2004; Hornby, 2011, 2014; Moles, 1999; Plan 2014; Porter, 2002; Shah Thapa, 2012; Turnbull et al., 2000; UNESCO, 1994). For the purpose of this section, the determinants that are reported consistently across research are clustered into six main themes, namely: attitudes towards disability and families; socioeconomic conditions of parents; relationship between parents and teachers; knowledge and awareness; language, communication and culture; and logistics and accessibility. Each of these determinants are discussed in the following sections in turn. However, some determinants that are reported by only a few studies are not detailed in this review. For example, Trainor's (2010a; 2010b) research from the USA points out that 'cultural and social capital' of parents is a unique factor affecting parental engagement, and Chindanya's (2011) study from Zimbabwe found that 'parent attitude towards a child's gender' is a unique determinant of parental engagement.

Attitudes towards disability and families

The attitudes of a society towards people with disabilities and their families shape the efforts and practices targeted towards inclusivity. Negative attitudes can be a hindrance to parental engagement in inclusive education (Altieri, 2001; Family Empowerment and Disability Council [FEDC], 2012; Rainforth & England, 1997). UNESCO (2005) observes that 'teacher attitudes and tolerance are the vehicles for the construction of an inclusive and participatory society' (p. 17) and 'implementing inclusion needs societal change in attitudes first' (p. 22). This suggests that negative attitudes of just one type of contributor will be detrimental to the engagement of other contributors in special needs education.

Nepalese studies also report that attitudes are a barrier to schooling of children with disabilities, although they do not relate it directly to parental engagement. Plan (2014) refers to caregivers' and teachers' negative attitudes as influential factors in the effectiveness of special needs education. Lamichhane (2013) also found that negative attitudes of parents and professionals are one of the significant barriers to education of children with disabilities. As such, the existence of parental negative attitudes towards the education of their children with disabilities means there is little hope of increasing parental engagement in schools without specific strategies in place to address parents' and professionals' attitudes. The views of Nepali scholars correspond with an earlier observation of Peters (2004), made in the context of India, that negative parental attitudes are a significant barrier to attendance and participation of children with disabilities. Moreover, attitudes towards disability in a society are likely to influence parents' level of stress, and their strategies of coping and becoming resilient and thereby their engagement. Singal (2016b) in her study in rural India indicated that parental engagement is influenced by their stress, ability to cope with grief, their levels of resilience, their child's medical condition, and their coping strategies and priorities.

Socioeconomic condition of parents

Financial hardship, such as parents living below the poverty line, is a significant barrier to parental engagement. Rainforth and England (1997) observed that parents' resources 'have the greatest effect on their ability to participate in their children's education' (p. 88). Survival issues become paramount for families living in economic hardship and hence socioeconomic conditions largely determine the everyday chores of family members. According to Moles (1999), 'For these parents, basic survival, childcare, and health needs often interfere with their participation in school events' (p. 32). Children with disabilities require additional time and care which further reduces parents' time to engage in their children's education. In addition, lack of facilities, such as ramps or assistive technology, may demand effort from parents that could impede their engagement in educational activities. Studies also highlight that unavailability of time due to parents' strict work schedules diminishes their commitment towards their child's schooling (Tederera & Hall, 2017).

Economic barriers arise from unemployment, lack of education and poverty. This is particularly the case in Nepal, since Nepal is one of the least developed countries where many people are unemployed and face difficulties earning a livelihood (CBS, 2012; World Bank, 2019). More than two thirds of Nepalese are dependent on traditional subsistence-based agriculture, 81% live in rural areas and 23% live below the poverty line, that is, they earn less than two dollars a day (CBS, 2012). For a family struggling to meet their basic requirements for survival, activities that are not compelling, such as engagement in school activities, do not attract them and hence are more likely to be avoided. Furthermore, many parents in Nepal need to move away from their home in search of work. Therefore, they are likely not to attend schools on a regular basis. Additionally, Plan (2014) found that many parents assumed education in special schools would cost more and therefore did not pursue this option. In such cases, parents tend to be indifferent towards their child's schooling and may even fear the extra burden that might be demanded by schools in the name of their engagement.

Relationships between parents and teachers

The differing status of parents and professionals and the nature of societal and school structures and hierarchies are cited as obstacles to parental engagement (Singal, 2016b). While, historically, in developed countries, the drive for inclusive education emerged from parents' initiatives, later, parents were viewed as passive receivers of inclusive education services (Bissaker, 2015; Chen, 2013; de Boer et al., 2010; FEDC, 2012; Peters, 2004; Turnbull et al., 2000, 2013; Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011; Wong et al., 2015). As these schools 'became a more formalized institution, parents became less personally involved in their children's education' (McKenna & Millen, 2013, p. 14). This means the advent of formal school structures eventually caused a decrease in the level of parental engagement. A possible explanation for this could be that, as teaching started to be viewed as a profession, it gave more privileges to teachers and therefore parents were expected to be supportive of their actions without questioning their authority. Parents were viewed as passive receivers of professionals' instructions, and were not invited to challenge professionals' power and expertise.

Studies point out that professionals tend to detach themselves from families and find difficulty connecting with parents. This attitude of professionals is a significant barrier to parental engagement (Burrows, 2011b; Carney et al., 2007). Similarly, Porter (2002) claims that professionals hold 'the decisive role as experts who "knew what was best" for children' (p. 21). It is argued that teachers do not feel comfortable in shifting power to parents. For example, research from the USA identified 'the disparity of power and authority in the relationship between parents and professionals' as a major challenge to successful partnerships (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004, p. 169). Beveridge (2005), in the UK context, highlights that, within the traditional expert model of partnership, professionals tend to rely 'exclusively' on their own wisdom to make decisions about interventions targeted to children with disabilities. Sometimes they may seek information from parents, but they do not share the decisions until they are in place. Therefore, professionals' 'decisions take little, if any, explicit account of parental views' (Beveridge, 2005, p. 95). This professional dominance seems to be prominent in developing countries like Nepal, especially given the hierarchical nature of society (Carney et al., 2007). Nepali parents, as in India (Singal, 2016b), lack efficacy or 'social power to complain' to the authorities due to their 'positions in the social hierarchy' (p. 39). This implies that they view teachers and professionals as above them in the hierarchy and tend not to question their authority.

Scholars from countries like the USA and Australia are critical of unequal relationships between parents and professionals including school staff. For example, Cefai and Cavioni (2014) from the USA oppose the view that 'parents should not "interfere" in their affairs' (p. 153) and Prater (2010) from Australia argues that 'it is a mistake to rely solely on the ideas of experts and ignore the real people, most knowledgeable about the child, the families' (p. 791). In such cases, it is suggested that professionals need to come forward to foster collaboration and establish productive relationships with parents. Cefai and Cavioni (2014) similarly highlight three successful practices for effective partnership with parents: building 'trusting collaborative relationships among teachers, families and community members'; addressing 'families' needs and class and cultural differences'; and sharing 'power and responsibility with parents/caregivers and families' (p. 153).

Awareness and education

The lack of awareness and knowledge on the part of both parents and teachers about disability, about the rights of children to an education and parents' right to participation has been cited as a barrier to parental engagement (Barriga, 2011). This is often the case in a developing country like Nepal, given the paucity of awareness programs to educate parents and teachers about such issues. Barriga's (2011) study found that Nepalese parents lack awareness about children's and their own rights. CERID's (2008) emphasis on the need for awareness programs for parents of children with disabilities in Nepal concurs with Barriga's study. Moreover, according to Barriga (2011), teachers also do not have 'enough knowledge' and awareness about how to recognise and cater for the differential needs of students with disabilities and their parents and to advance inclusive education (p. 48).

If up-to-date information about services that parents need for their children is at professionals' disposal, it helps progress parental engagement. This information and services may include child-specific information; assessment and identification; participation in planning; social support; advocacy; transition planning; respite care; counselling; coordination of services; and referral services (Porter, 2002). As parents who lack knowledge about services for their children are less likely to be involved in school affairs, the lack of such information on the part of professionals results in decreased parental involvement in schools.

Misunderstandings of both parents and professionals may further impede parental engagement. Misunderstandings may arise due to parents' and teachers' differing 'beliefs, values, knowledge and understandings related to children's development and learning and to aspects of educational provision' (Beveridge, 2005, p. 99). Such misunderstandings can also be attributed to parents' unfamiliarity with the school system and teachers' ignorance about cultural and religious diversity, due to which teachers 'can make unfounded assumptions about family life' (p. 50). However, 'educators can work more effectively when they have information from parents' (Porter, 2002, p. 20). Therefore, awareness and education programs for both parents and professionals are considered necessary.

Language, communication and culture

Language, communication and sociocultural factors are further determinants of parental engagement in special needs education. Turnbull et al. (2013) view 'communication' between educators and parents with special needs children as the most important 'principle of partnerships'. However, technical/educational jargon used in school may be unfamiliar to parents and therefore parents may feel unwilling to interact with schools (Pokhrel, 2004). If teachers and parents speak different languages, that further impedes participation. According to scholars, communication barriers appear due to the presence of top-down relationships, differences in culture, the diverse language backgrounds of the community, insensitive use of language, and uncaring attitudes towards parents and children with disabilities (Beveridge, 2005; Chen, 2013; Hornby, 2014; Rainforth & England, 1997). Burrows (2004) in her study in South Australia argues that a strong home–school relationships with a sensitive understanding and empathic approach is very important to reduce this communication barrier.

Attention to quality of communication in Nepal is highly relevant given it is a multilingual and multicultural society. Nepal officially records 123 different languages spoken by 92 different ethnic groups (Yadava, 2007), suggesting a vast diversity in language spoken in the schools and implying that communication could be a potential barrier to parental engagement. In such a context, treating people justly, listening to their voices and acting compassionately is of importance and how parents reflect on their communication with schools is of interest to this current research.

Logistics and accessibility

Logistics have been mentioned in the literature as a further obstacle to parental engagement. Logistics includes school accessibility, distance from home to school, transportation and disability-friendly facilities (Barriga, 2011; FEDC, 2012; UNESCO, 2009b). Beveridge (2005) mentions 'transport arrangements' and 'domestic and work commitment' (p. 2) as barriers in the context of the UK.

Plan (2014) stresses transportation from home to school as a crucial issue for children with disabilities in Nepal. Currently most parents of children with disabilities send their children to residential schools, which are, for most parents, located at a distance from their home. While this may remove the daily concern of how to reach school (especially in mountainous areas) it also presents as a challenge to regular engagement in their child's education. As such, distance becomes a determinant of these parents' engagement in their children's schooling. Even if a child is able and welcome to attend the local school, other determinants, such as poor infrastructure including a lack of disability-friendly facilities, difficult and rugged terrain, and lack of reliable transportation services, may restrict parental engagement. In addition, minimal or no assistive resources in Nepal also has resulted in low motivation on the part of parents to engage in children's learning (Shah Thapa, 2012).

2.4.7 Theoretical models for engaging parents

Scholars, mainly from the West, offer a number of theoretical models (sometimes also called frameworks) related to parental engagement. These models are pertinent to parental engagement both in mainstream education (Epstein, 2001, 2011; Deslandes, 2009; Hoover-Dempsey & Sandler, 2005; Emerson et al., 2012) and special education settings (Hornby, 2011; Porter, 2002; Turnbull et al., 2000, 2013; Beveridge, 2005). In this section, six different theoretical models are presented. Each model is discussed in the light of its relevance to the context of special needs education in Nepal.

Framework of six types of involvement

Joyce Epstein (2001, 2011) offers a framework of parental involvement which acknowledges school, community and parents as the key agents for schools' outcomes. As these three entities – school, family and community – overlap and influence each other, this framework is also known as 'overlapping spheres of influence' (Emerson et al., 2012; see also Deslandes, 2009). This framework is drawn from the ecological model of Bronfenbrenner,[10] which considers multiple environmental factors that shape the lives and experiences of children with disabilities and their families. Epstein argues that positive interactions and partnerships among school, family and community result in students' growth. According to this framework, parents can be involved in the schooling of their children in six different ways, as described briefly in Table 2.2.

Table 2.2: Epstein's six types of parental involvement

Type	Meaning
Parenting	Parents develop understanding of child development and professionals help families to do so
Communicating	Professionals design two-way communication between school and home relating to school programs and children's progress
Volunteering	Schools invite parents' support in the classroom
Learning at home	Families are provided with information and ideas on how to help students at home with curriculum-related activities, course choices and homework
Decision making	Schools include parents in school decisions, programs and plan development; all major groups are represented on the school committee
Collaborating with community	Schools identify and integrate resources and services from the community in order to strengthen school programs, family practices and student learning

Source: adapted from Epstein (2001, 2011); see also Deslandes (2009).

The framework details schools' tasks to involve parents meaningfully, in which schools are asked to be very active in promoting family involvement. This framework places child achievement at the core. The framework is expected to yield the best results when the interests of all three entities overlap. However, schools shoulder more tasks because 'partnership [is] centred on the school's agenda' (Baquedano-López, Alexander, & Hernández, 2013, p. 150). As such, the model may not result in genuine engagement of parents, as it seems that the parents' role is to carry out what they

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[10] Bronfenbrenner's ecological theory maintains that the growth and development of a child is heavily influenced by the interaction of the inherent qualities of a child and his/her environment. It is crucial to study multiple environments or ecological systems to properly grasp the child's development (Bronfenbrenner, 1994).

are directed to do. This model, given limited resources and understandings about models and approaches, seems to be complicated to implement in Nepal.

Parent role construction and efficacy model

According to Hoover-Dempsey and Sandler (1997, 2005), parents' perceptions about their roles in school and their efficacy (belief about their own capacity for involvement) largely shape parental involvement at school or home. This model draws on Bandura's role theory (people act in a predictable way as per broader social expectations and avoid performing in conflicting roles) and self-efficacy theory (one's beliefs in one's own strength and ability heavily shape performance and results) (Deslandes, 2009). In this way, parents' perceptions about invitations for their engagement (by school, teacher or child) and their life context (skills/knowledge, time and energy) contribute to determining the level of their engagement (Deslandes, 2009). In this regard, Deslandes (2009) states, 'parents will persevere in their efforts and expect success if they believe they can control desired outcomes' (p. 6). If they believe that their involvement is going to bring about changes in their children's progress, they are more likely to participate in the school's activities, while if they believe that success is dependent on children's ability, luck or fate, they become reluctant to take part in the activities (Deslandes, 2009). Hence parental belief about both their anticipated roles and their capacity plays a critical role in shaping their engagement. Moreover, while Epstein's model emphasises the role of the school/educators in enhancing parental engagement, this model puts more emphasis on the parents' side of school–family collaboration (Hoover-Dempsey & Sandler, 2005).

In Nepal, no research has investigated the level of parental involvement in schools based on their self-efficacy and role construction. However, some studies have concluded that success of schooling is determined by parents' beliefs about the education and schooling of their children (Carney & Bista, 2009; Parajuli, 2007). Those beliefs could be a possible source of parents' willingness or unwillingness to participate in school affairs, which is a key interest of this research.

Seven dimensions of parental engagement

Emerson, Fear, Fox and Sanders (2012) have identified seven key dimensions of parental engagement, which have been adopted by the Australian Government's Department of Education as the 'Family School Partnerships Framework'. These dimensions of parental engagement are: communicating; connecting learning at home and at school; building community and identity; recognising the role of the family; consulting for decision making; collaborating beyond the school;

and participating (Emerson et al., 2012, pp. 28–29). A brief description of each dimension is presented in Table 2.3.

Table 2.3: Seven dimension parental engagement model

Dimensions	Explanation
Communicating	School leaders and teachers build relationships that encourage, facilitate and leverage parent and family engagement and ultimately enhance students' learning
Connecting learning at home and school	School staff, parents and families recognise and appreciate the overlap between home, school and community learning environments, and work collaboratively
Building community and identity	Supporting students to develop their sense of identity, personal competence and belonging. In doing so, they value and draw on school, family and community relationships, cultures and traditions
Recognising the role of the family	When school staff, parents and families appreciate their complementary roles in children's learning and schooling, they increase their collective positive influence
Consulting for decision making	Inclusive school decision making generates shared responsibility and school accountability
Collaborating beyond the school	Community engagement enriches student learning and wellbeing and expands school and family resources
Participating	Participation includes involvement in school-based activities, engagement in school-based learning, as well as activities that are not directly related to schooling. It is important to value, recognise and celebrate the contributions made by families through volunteering their time, talent, resources and networks

Source: Emerson et al. (2012).

As detailed in Table 2.3, this model provides a useful tool or a 'ready-to-go' guide for practitioners and schools who wish to engage parents and communities in their workplace. When we look at the detail of this model, each step subtly captures the nuances of challenges, difficulties and contextual aspects of parental engagement, so with a little adaptation it could be used in other contexts such as in Nepal.

The pyramid model of parental involvement

The pyramid model of parental involvement takes into account both the needs of parents and the contributions they can make to the successful schooling of their children (Hornby, 2011). While the models discussed above in this section focus on mainstream schooling in general, Hornby explicitly relates his model to the context of special needs education. According to this model, we can expect different contributions from parents at varying levels, such as information from all, collaboration from most, resources from many, and policy ideas from some parents (see Figure 2.3). The contributions from parents are not however unconditional. They are gained only when parents' needs – such as communication, liaison, education and support – are addressed. Thus, educators are required to work to address parental needs, while parents in turn contribute to school activities. Both parents and teachers' time and expertise are required in order to enrich parental engagement. However, no literature is found in the context of Nepal in relation to the applicability of this model of parental engagement.

	Parental contributions
Some	Policy formation (e.g. PTA members, school governors, parent support/advocacy groups)
Many	Acting as a resource (e.g. classroom aides, fundraising, supporting other parents)
Most	Collaborating with teachers (e.g. home–school reading, maths and behaviour programs)
All	Sharing information on children (e.g. strengths/weaknesses, interests, medical details)
All	Channels of communication (e.g. handbooks, newsletters, telephone, homework diaries)
Most	Liaison with school staff (e.g. home visits, parent–teacher meetings)
Many	Parent education (e.g. parent workshops)
Some	Parent support (e.g. counselling, support groups)
	Parental needs

Source: Hornby (2011, p. 33).

Figure 2.3: The pyramid model of parental involvement

Parent–professional relationships focused model

According to Porter (2002), it is the type of relationship between parents and professionals that determines the level and quality of parental engagement. Porter described a continuum of parent–professional relationships starting from professional dominance (a form of relationship which seeks only compliance from parents) to parents as employers (who can direct the process of children's schooling). The types of parent–professional relationships and the ways that parents' roles are shaped by each type of relationship, are presented in Table 2.4.

Table 2.4: Parent–professional relationships and parents' roles

Relationships	Anticipated role of parents
Professional dominance	Compliance and passivity
Routine communication	Acceptance of decisions
Parallel cooperation	Involve in fringe or peripheral activities
Coordination	Learn skills deemed by professionals to be necessary
Collaboration	Share power but choose their own roles and level of involvement
Employer–employee	Parents as the employers direct the programs so that teachers as employees meet their child's needs

Source: Porter (2002, p. 22).

Along with evolving trends in parent–professional relationships, Porter (2002) presents a family-centred model, which comprises three key aspects: building rapport with parents (to achieve the desired goals); parents' participation in decision making (to empower them and give them confidence); and professionals equipping parents with crucial relational skills (such as positivity, sensitivity, responsiveness and friendliness) (Porter, 2002, pp. 22–32). In Nepal, the relationship between parents and professionals currently trends towards professional dominance due to the existing hierarchical structures of language, gender, class, geography and caste (Acharya, 2007). However, as this model is comprehensive, simple and respects both professionals' and parents' roles in collaboration and as it seems transferable across different contexts and cultures, this model could be of use in the Nepalese context.

Empowerment model

According to Turnbull et al. (2000, 2013), engagement of parents is very much dependent on the power relationships that exist between parents and professionals. Turnbull et al. (2000) describe a continuum of power relationships among families and professionals with the help of such terms as 'power over', 'power with' and 'power through' (p. 630). In power-over relationships, professionals have control over parents through resourcing and decision making. Professionals are perceived as more competent in these aspects. Secondly, power-with relationships are cooperative bonds between parents and professionals, where decisions are made and resources are shared mutually since both parties are considered as having equal competence. Finally, the power-through relationship is a process which provides benefits to both parents and practitioners as they gain competence and abilities and acquire resources from each other. They do not challenge the power of their counterparts. In this approach, more synergistic outcomes are expected, which yield an effect greater than the sum of its parts (Dudley, 2017; Turnbull et al., 2013). This conceptualisation of family–professional relationship focuses on collective empowerment. In this model, power is not seen as a means of controlling decisions or resources; rather it is used to build the capacity of whole communities involved in the process.

Power relationships between teachers and professionals in Nepal are likely to be shaped by the caste system, class, cultures, ethnicity, education, gender, geography and so on (Bista, 1991; Dahal, 2002; Shrestha, 1998). According to Nepali scholars such as Shrestha (1998) and Bhattachan (2005), local lay people including parents are considered inferior and less knowledgeable. Experts and professionals think that parents lack knowledge and need more 'awareness' programs (CERID, 2004, 2008). Therefore, the empowerment model could be of relevance for Nepal. As this model describes power as a developmental process, it can be translated into a context where there is currently little or no power so that eventually power can be shared as parents and professionals become familiar with the concept of power sharing.

The theoretical models or frameworks discussed in this section may provide professionals and schools with direction and areas of focus in working collaboratively with parents. Models that are too prescriptive, however, may not work because ‘the one-size-fits-all approach is inappropriate’ (Prater, 2010, p. 790). Overall, most of the models seek a change in the existing relationships between professionals and parents as currently most power is considered to rest with professionals.

2.4.8 Practical strategies for promoting parental engagement

Research, mainly from western contexts, reveals an array of practical strategies that could promote engagement of parents. Emerson et al. (2012), from Australia, describe a number of strategies that are important for effective parental engagement, namely, communication, targeting interventions according to the parents’ and their children’s needs, support for parents of different age-group students, and different strategies for different cultural groups. They argue that ‘successful parental engagement strategies focus on local needs and contexts, incorporate a variety of communication channels, and are flexible in how engagement is defined’ (p. 12). They think that identifying and addressing the contextual factors affecting parental engagement are crucial to improve parental engagement. For example, according to Emerson et al. (2012), for refugee parents, factors such as ‘the process of resettlement’, ‘limited experiences of formal schooling prior to their arrival’, ‘school expectations of their involvement’, and the expected ‘new role as the schools’ partners’ could prevent them from participating in schools (p. 48). So, they state that Australian schools have tailored their efforts in accordance to the parents’ needs to invite them into the schooling processes. These authors showcase examples of some successful strategies that are practised in Australia. They include ‘community gardens’ where families grow and share produce, English classes offered by English language teachers for refugee parents, multicultural women’s groups, and ‘Saturday workshops’ to provide information and to listen to the families’ concerns (p. 49).

Similarly the Virginia Department of Education (2010) in its report from the USA identifies six strategies to involve parents in schooling activities, namely, ‘hosting events and activities that bring parents and families into the school’, ‘communicating with parents frequently, using a variety of methods’ (such as mail, phone, email, communication notebooks, face-to-face meetings), ‘creating a warm, respectful, and welcoming school environment’, ‘being flexible in accommodating parents and families’, ‘providing a variety of resources for parents’, and ‘supporting parents in helping their children at home’ (pp. 2–8). The report also suggests organising events, such as ‘cake with the counsellor', 'coffee with principal', 'parents and pastries', 'three for me' (three hours volunteering), 'families and schools together' and so on to encourage parental engagement.

Similarly, Clare Campbell (2011) in the UK suggests a set of strategies to encourage the involvement of hard-to-reach parents in school, which include training for parents so that they can learn to work with children and gain confidence to interact with professionals, helping parents to recognise their role as partners by allowing a suitable platform for them to critique and formulate agendas, giving parents significant roles in school decision making, and communicating with parents about their roles in children's outcomes. Campbell (2011) further argues:

> It is possible to harness new technologies for parental communication purposes through the use of school blogs and podcasts, a school website (regularly updated) and online questionnaires and resources in order to reach at a distance those who are unable or unwilling to engage with the school in person. (p. 18)

While high quality technology infrastructure is still wanting in Nepal, the majority of people have access to mobile phones with data, which provides one option for increasing communication with families considered hard to reach in Nepal.

School–Home Support (SHS) (n.d.), also from the UK, presents a number of practical ways to work with parents in context-specific settings. They propose school professionals internalise the key principles underpinning parental engagement, such as trust, non-judgement, empathy and respect. They state that some strategies, though they seem very simple, are effective in this regard, such as talking with colleagues about parental engagement, sending letters to parents via their children, conversing with parents in the morning at the school gates, and finding information about other services available near schools and conveying it to needy parents. This approach would require a parent to have their child attending a local school which they connect with on a daily basis. However, in Nepal, as many children with disabilities stay in school hostels and some go to schools with older siblings, there are limited opportunities to interact with parents. The study also suggests ways to encourage engagement of families with complex needs, caused by poverty, migration, language difficulties, negative attitude to education and work pressure (SHS, n.d.). Although they all have 'complex' needs, they may need very different support, resource and interventions. In such cases, the key to successful engagement is 'to be able to meet parents "where they are" on both an emotional and cognitive level' (SHS, n.d., p. 52). Just as labels such as 'hard-to-reach' or 'parents with complex needs' do not define their actual needs, so too the 'true' needs of a family need to be investigated carefully (SHS, n.d., p. 52).

Quality communication has been identified as crucial in promoting parental engagement and in building strong parent–teacher relationships. According to Turnbull et al. (2013), communication is 'verbal, nonverbal, or written messages that partners exchange among themselves' (p. 89). To them, 'communication is especially important to engage in empathetic listening and to carry out strategies that are individualized according to each family's communication preferences' (p. 102). Professionals need to be friendly, listening, clear and honest and should provide and coordinate information according to the needs of parents. Burrows (2004) from Australia finds that compassionate communication is a promising approach to working collaboratively with the parents of children with disabilities. Burrows asserts that parent–teacher relationships require a sensitive, understanding and empathic approach. Porter (2002), also from Australia, finds that levels of parent engagement depend on professionals' behaviours and actions. If parents trust in the professionals, they are cooperative and ready to listen to professionals and to act accordingly. She argues that professionals could work more efficiently if they prioritise listening to parents. Porter (2002) also calls for a type of communication based on trust and mutual respect, which in turn requires, on the part of professionals, three clusters of communication skills: 'listening', 'being assertive', and 'solving problems collaboratively' (p. 32).

Strategies discussed in this section have some relevance in the Nepali context in the sense that they indicate different interventions targeted to effective engagement of parents in general as well as in the context of special needs education. However, as the researchers suggest, the strategies should be taken as fluid and flexible so that they can be customised to fit the existing cultural and contextual variations. The literature described above did not cover context-specific issues, for example, the engagement of parents whose children live in school hostels, which is most often the case for the parents involved in this research. In this case, distance is a significant parameter that determines their engagement. Such contextual issues are of particular interest to this research.

2.5 Chapter summary

This chapter has presented an overview of literature of relevance to the research design and includes a focus on disability, inclusion, special needs education, parental stress and coping, and parental engagement. A balanced view of disability is one that represents disability as a confluence of the person's physiological conditions and social situations. Inclusion movements, especially those of the 1960s and onward, have been influential in ensuring the rights of people with disabilities and in helping them access mainstream services including education. While the movement originated in developed countries, it later expanded to developing countries like Nepal through international measures such as UN declarations. If implemented genuinely, education as an intervention can serve both as a means to raise awareness about inclusion and as an end. As argued in the literature, for effective implementation of education as intervention, engagement of all relevant agents including parents of children with disabilities in school activities is important. In addition, international research presents several determinants of the level and quality of parental engagement, such as attitudes, economic status, parent–teacher relationships, awareness, communication and logistics. However, in Nepal, there is a paucity of research-based knowledge pertaining to these areas. Based on the experiences of the West, several theoretical models and practical strategies are suggested to effectively engage parents in school processes. The literature also suggests that context- and culture-specific approaches, tailored to parents' circumstances, are needed to engage them meaningfully. Therefore, the models and strategies developed and practised elsewhere may serve as useful resources for Nepal, but prior to such considerations this research is designed to address gaps in the research on parental experiences and engagement in raising and educating their children with disabilities in a rural context in Nepal. The next chapter presents the methodological foundations and research design of this research.

CHAPTER 3 - METHODOLOGY AND METHODS: EXPLORING PARENTAL ENGAGEMENT THROUGH RELATIONAL-CENTRED INQUIRY

> What we can learn and know about another arises within the intersubjective space between. In this zone of ambiguity and uncertainty, the unforeseen hovers and layered meanings invite discovery. (Finlay, 2009, p. 1)

3.1 Introduction

This chapter deals with the methodological considerations and methods that underpin this research. The choice of methodology is a philosophical one, informed by worldviews about the nature of knowledge; while methods reflect the activities, strategies and techniques used to obtain knowledge (Finlay & Evans, 2009; Green & Browne, 2005; Lessem & Schieffer, 2016). Finlay and Evans (2009) use the metaphor of a voyage to describe a research project, with methodology operating as a flexible guide map and methods being the routes and vehicles that enable researchers to get there. The chapter begins with a brief discussion of qualitative methodology, which includes a discussion of relational-centred inquiry and narrative approach. In the following section, I outline the different methods employed in the research for selecting the site, recruiting participants, data gathering, data analysis and addressing the ethical concerns of the research. The selection of qualitative methodology for this research is regarded as fit for the purpose given the emphasis on eliciting parents' and education professionals' experiences and insights.

3.2 Qualitative methodology

Qualitative methodology, as described by various scholars, is considered as a suitable approach to explore the subjective experiences, feelings, beliefs, viewpoints, relations and interactions of research participants in a naturalistic setting (Finlay & Evans, 2009; see also Blue-Banning et al., 2004; Creswell, 2012; Denzin & Lincoln, 2011; Merriam, 2009; Wike, 2015), unlike positivist methodologies which focus on laboratory or other more controlled settings (Anderson, 1998; Brandt, 2015; Denzin & Lincoln, 2011; Tuli, 2010). Creswell (2012) argues that a qualitative approach to research is suitable for studies aimed at giving participants a voice, in addition to expanding understandings of complex issues. For Liamputtong (2007), qualitative research allows

> researchers to be able to hear the voices of those who are 'silenced, othered, and marginalized by the dominant social order', as the methods 'ask not only "what is it?" but, more importantly, "explain it to me – how, why, what's the process, what's the significance?"'. (Hesse-Biber & Leavy, 2005, p. 28, as cited in Liamputtong, 2007, p. 8)

Since the main aim of this research was to elicit the as yet largely unheard voices, experiences and insights of parents and local educational professionals from a remote and rural area in Nepal, a subtle, nuanced and relational methodology sensitive to the complexities of social and cultural issues was needed (Liamputtong, 2007). There is growing evidence of the use of qualitative research in special education research. See for example Blue-Banning et al. (2004) who used a qualitative approach for their study on collaborative partnerships between parents and professionals. They found it enabled them provide voice and context to parent participants (Blue-Banning et al., 2004, p. 135). In addition since qualitative methodology is flexible and able to be adjusted to meet the needs of participants (Liamputtong, 2007), it was highly suitable for this study given the hard-to-reach participants and sites.

3.2.1 Relational-centred research

Given the focus of this research on eliciting in-depth experiences and insights of parents and professionals, a relational-centred inquiry was found appropriate. According to Finlay and Evans (2009), relational research is needed when exploring phenomena that arise from the interaction of research and research participants. A relational approach emphasises developing a relationship with the participants, as opposed to conventional research that generally does not encourage such interpersonal familiarity (Curry & Wells, 2006, p. 16). Relational-centred research allows researchers ‘to form relationships with participants, which gradually leads to the establishment of trust and rapport’ (Liamputtong, 2007, p. 8). Relational research views research participants with great respect, seeing them as ‘co-researchers’ in the research journey (Finlay & Evans, 2009; see also Burrows, 2011b). As ‘understandings of other are found in the fullness of our open relation’, mutual participation is important in all phases of the research where we allow ‘dialogue, parity and reciprocity’ (Finlay & Evans, 2009, p. 160). Relational-centred research views research as a ‘joint product of researchers and participants (and readers) and the relationship they build’ (Finlay & Evans, 2009, p. 6). In this regard, Thayer-Bacon (1997) writes, relational research ‘opens possibilities for valuing contributions from all people’ (p. 240).

According to Finlay and Evans (2009), a research undertaking is like ‘an adventure into uncharted territory’ (p. 10). Such an adventure acknowledges the ‘complex and multifaceted’ nature of our relationship with others (Burrows, 2011b, p. 32). The research progresses by acknowledging the knowing of both researchers and participants. Therefore, in a relational approach to research both parties have equal respect and their relationship is built on the principles of mutuality, reciprocity, compassion and morality. According to Finlay and Evans (2009), the relationship between researcher and participants can be described as an ‘I–Thou relationship’ in which each person accepts and becomes open to the other. They further argue that this type of relationship is ideally ‘free from judgement, narcissism, demand, possessiveness, objectification, greed and anticipation’ (p. 31).

Researchers are encouraged to ask themselves questions as to ‘how this knowledge will enhance my responsiveness to people/families’ (Doane & Varcoe, as quoted in Burrows, 2011b, p. 31). As Longbottom points out, this requires ‘real commitment, great flexibility and openness to doing things differently, along with the appropriate skills’ (quoted in Burrows, 2011a, p. 7).

Relational research calls for researchers to try to suspend their prejudices and be open and ready for self-disclosure, and to be passionate about learning from their participants/co-researchers (Burrows, 2011b; Finlay & Evans, 2009). Finlay and Evans (2009) present ten core values that underpin relational-centred research: owning oneself, integrity, reflexivity, acceptance, agency, empathic inquiry, mutuality, openness, impact and humility (pp. 36-39). The first three values relate to the researchers; the next three relate to research participants, ‘mutuality’ and ‘openness’ to the research relationships; and finally, ‘impact’ and ‘humility’ are associated with the research outcomes. These concerns are also pertinent to the ethic of relational research, which will be discussed later in this chapter. The relational approach to this research is further supported through the inclusion of a narrative approach that has the capacity to highlight the richness of perspectives, experiences, contexts, cultures and values that deeply inform this study.

3.2.2 Incorporation of a narrative approach within relational research

As this research involves the collection of experiences and insights of parents of children with disabilities and professionals who are close to those parents, it seemed appropriate to extend the relational approach through a narrative orientation in both methodology and methods to make sense of and depict the co-researchers’ experiences and insights. For Clandinin and Connelly (2000) ‘experience happens narratively’ (p. 19) and hence can be best expressed in the form of stories. As a data analysis approach, ‘Narratives can open up a deeper view of life that is derived from real events, feelings and conversations, as well as exposing those experiences which might otherwise not be heard or read’ (Clough 2002, as cited in Burrows, 2011b, p. 36).

According to Riessman (2001b), a narrative approach to research is particularly helpful in understanding the experiences, perceptions and feelings of vulnerable people. Relational research, when supported by the narrative approach, invites research participants or co-researchers to recall their personal experiences, and in doing so acknowledges that they also create meanings from their stories in connection with their environments (Connelly & Clandinin, 1990; Clandinin, 2006; Lutovac & Kaasila, 2010; Polkinghorne, 2010). Lutovac and Kaasila (2010) contend that ‘personal narratives no matter how unique and individual are inevitably social in character’ (p. 93). In this sense, stories are relational in nature as they illustrate the broader picture of storytellers’ community or society as demonstrated by everyday happenings. This highlights the complementarity of the relational and narrative approaches in qualitative research, as adopted for this research.

The narrative approach brings to the fore the voices of those who are usually unheard, silenced or rarely represented in the academic environment (Brantlinger, Jimenez, Klinger, Pugach, & Richardson, 2005; Cuku, 2014). Bell (2002) maintains that 'narratives function in opposition to elitist scholarly discourses and that their use in research offers an opportunity for marginalised groups to participate in knowledge construction' (p. 209). As such, the narrative provides a voice to those whose voice is seldom heard before. Since the life experiences of parents and local level professionals in Nepal have not been given much research coverage, and their voices largely remain unheard, in such context, a narrative approach in combination with a relational approach was found to be suitable.

In addition, the narrative approach is particularly suitable for this research since Nepal is a storytelling culture, and knowledge about culture, history, livelihood and environment has been transmitted through oral storytelling from generation to generation (Davis, 2014). Every tradition, custom, ritual or place in Nepal is connected to ancient stories and myths. In this way, folk stories provide a window into people's social worlds, as well as their very sense of self (Davis, 2014). The narrative approach, therefore, enables the researcher to articulate participants' stories, connecting them with their cultures and contexts. Possibly due to this feature of the narrative approach, Duke and Mallette (2011) view it as a form of grassroots or people's methodology.

The choice of narrative approach in this research is deliberate. It aligns well with the research objectives related to participants' experiences and insights. A narrative approach to research has been used widely in the education field, and more particularly in the special education sector in the international arena. As a particular example, McDermott-Fasy (2009) employed a narrative inquiry approach and collected stories of parents of children with disabilities with an aim to understand what those stories would tell about their perspectives regarding parent-professional partnerships. Moreover, there are increasingly frequent examples of the use of narrative approach in studying disability (Pearce, 2009), partnerships in special needs education (McDermott-Fasy, 2009 Desai et al., 2012; Jackson, 2004), and parental experiences (Barriga, 2011; Hillian, 2015). Hillian (2015) particularly emphasises the benefits of the narrative approach to study the phenomenon of parental engagement and has compared other qualitative methodological designs including for example phenomenology, ethnography, grounded theory and case study and found the narrative approach appropriate for any study whose focus involves 'analyzing stories parents told about their perceptions of involvement, giving an elaborate description of experiences' (p. 66). However, the narrative approach is not common in disability research in Nepal, although the work of Desai (2012) in India, and Pearce (2009) from Canada were useful to draw upon.

In the narrative approach to research, participants' voices are initially expressed in the form of narratives which are then retold as part of the findings of the investigation. In this light, as Mendieta (2013) argues, researchers are not just passive listeners, but 'are part of the story that is being told or created, both as characters and as narrators' (p. 139). Scholars have described the use of case-focused and theme-based narrative techniques for data analysis appropriate for the complementary forms of relational and narrative research (Ayres, Kavanaugh, & Knafl, 2003; Finlay & Evans, 2009; Riessman, 2001a). While case-focused narrative centres on detailing the issues found within the case chosen, thematic analysis tries to seek patterns and commonalities across the cases. As I elaborate in detail in Section 3.3.6, both techniques are used in this research.

3.2.3 Ontological and epistemological orientation of the research

For relational researchers, ontological questions about how we perceive reality, existence and/or being cannot be separated from our experiences of relationship with others (Thayer-Bacon, 1997). For Thayer-Bacon (1997) relational-centred research rests on a number of assumptions which include: 'all people are social beings', 'we are contextual social beings', and 'people have a past and have been affected by others' views' (pp. 240–242). Finlay (2009) similarly emphasises Halling's view that: 'To be a person is to live in the world with others' (p. 13). Only through our relationships with others can we develop a sense of self (Thayer-Bacon, 1997), which means that our sense of self and relationships with others exist reciprocally. This ontological orientation is in line with Grbich's view that 'self' is 'interlinked with others' (2004, as cited in Liamputtong, 2009, p. 17).

Relational-centred research draws on an epistemology that connects knowers and the act of knowing; that sees knowledge in relationships (Thayer-Bacon, 1997). Thayer-Bacon (2010) emphasises, 'we become knowers and are able to contribute to the constructing of knowledge due to the relationships we have with others' (p. 2). Thayer-Bacon maintains that knowing cannot be separated from knowers. Knowing is an activity like dancing or singing or loving which cannot be done without others. She describes 'knowing' as a dialectical (or dynamic, flexible and reciprocal) relationship between knowers and what they intend to know, and 'the quality of these relationships directly affects our abilities to become knowers' (p. 241).

According to Romm (2016), an epistemology of relational-centred inquiry 'sees knowing as a process of developing insights by people in relation with one another and with all that exists' (p. 44). For anthropologist Gregory Cajete, 'Everything is related, that is, connected in dynamic, interactive, and mutually reciprocal relationships' (2000, p. 75). While traditional positivist ways of knowing tend to detach knowers from what they attempt to know, an epistemology of relational inquiry calls upon knowers to engage with what they wish to know and understand in order to tap into collective wisdom (Romm, 2016). The next part of this chapter discusses the methods adopted in this research.

3.3 Methods guiding the research process

As stated above, if methodology is a guide or map (Finlay & Evans, 2009) then methods can be likened to routes or vehicles. In this section, I outline these routes and processes used for this research, such as while selecting the research site, accessing participants, gathering data, analysing them and addressing ethical issues.

3.3.1 Research settings

For this research, Kapilvastu District from Province Number Five of Nepal and three special integrated schools[11] from the same district were chosen as research sites. Kapilvastu is one of the poorest districts in terms of the Human Development Index (HDI) (measuring 0.432, ranking 59th out of a total of 77 districts) in the western region of Nepal (CBS, 2012).[12] I chose a location that would be accessible for me because I shared the same culture, religious beliefs and language, yet it was not a region I worked in during my career as an employee of the Ministry of Education. In addition, the selection of the site was based on convenience sampling (Creswell, 2012), as the district had a number of schools offering education to special needs children in an integrated model, known as a resource class.

The integrated schools for this research were chosen for a range of reasons: they were the biggest in terms of numbers of children with disabilities enrolled in Nepal and also in Kapilvastu; and they intended to move towards inclusive education provision – as the aim of integrated schools was to prepare children with disabilities for mainstream education through a program of intensive support (CERID, 2006, 2008). It was hoped that this selection would provide enough scope to elicit the voices, experiences and insights of parents and education professionals involved with children with disabilities. The box below presents a brief synopsis of the research sites and participants and their selection techniques.

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[11] In this research these schools are named School A, School B and School C.

[12] A detailed profile and information about the district can be accessed from the government portal (http://ddckapilvastu.gov.np/en/type/publications/).

Research settings: A synopsis

Research sites
A western Terai district of Nepal in Province Five with the lowest HDI (Kapilvastu)
Three integrated schools in this district

Participants/co-researchers
[A] Nineteen parents of children with disabilities for informal interview conversations
Parents of school-attending children (N = 13) and school non-attending children (N = 6) Total: 19
[B] Local professionals and community members for focus group discussions (FGD) Total: 23
Special education and mainstream teachers (FGD-1) N = 6
Head teachers and assistant head teachers (FGD-2) N = 6
Community members (school management + PTA members) (FGD-3) N = 3
Government officials (school supervisors, resource persons, assessment centre and village council officials) (FGD-4) N = 8

Sites and participants selection techniques
Sites selection: convenience sampling
Participants selection: self-selection, snowball sampling

3.3.2 Research participants/co-researchers

Parents of the children with disabilities and local professionals working closely (or supposed to be working) with these parents were selected as the participants in this research. The first group of these participants were the parents of children with disabilities of age range 5 to 18. Of this group, one third were the parents whose children who were not attending school. The second group of participants were local educational professionals, who included regular teachers and special education teachers in the selected schools, head teachers[13] and assistant head teachers, members of school management committees and parent–teacher associations of these schools, and local level government officials including resource persons, school supervisors, and staff at the assessment centre, District Education Office and municipality offices. While parents were asked to participate in individual interviews, professionals were invited to participate in one of four focus group discussions. I also chose the parents of non-school-going children because the chosen district was one of the least developed districts in the country, and it was anticipated that there would be a considerable number of children with disabilities who did not have access to schooling.

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[13] In Nepal, school principals are called head teachers. Previously, mostly in informal settings, people used to call them headmasters, but later with the growing sensitivity about the use of gender-inclusive words, they began to be called head teachers.

Parents were chosen because they are the ones who live with children with disabilities, who know the pain and pleasure of being with children with disabilities, know the reasons why they chose (or did not choose) a school for their children, and they have experience in working in school settings and with professionals regarding their children's education. Parents could offer rich data pertinent to the research about the experiences of living with and educating children with disabilities; therefore, they are best positioned to be research participants. Lately, I, as a government official working in a central department, felt that it was the parents' voice that was not present in meetings and discussions. However, it was rare that the importance of parents' engagement was mentioned other than by parents themselves. So, I wanted to talk directly to parents, listen to them, and generate knowledge informed by them.

Local professionals and community members were chosen in order to collect additional evidence to construct rich narratives. These participants were closely related to the parents chosen. According to McDermott-Fasy (2009), the views of other related persons in the research are important 'to get a full and accurate accounting of each situation described [for which] one would need to interview all parties involved' (p. 138). The aim of such choice, however, was not to validate the insights and experiences of parents; but to obtain additional information and crucial insights with an aim to intensifying the voices and concerns of parents and their children with disabilities. Moreover, as stated above, in this relational approach to research, these participants were viewed as co-researchers with incredible capacities to contribute to this research.

3.3.3 Participant selection procedure

Purposive sampling that comprises a mix of 'self-selection' and 'snowball' sampling was employed to access participants/co-researchers in this research (Poet et al., 2011; Creswell, 2012). The self-selection approach involved head teachers' distribution of my recruitment materials (letter of introduction, information sheet and consent form) to all eligible parents, schoolteachers and community members. The interested participants themselves were invited to contact me to show their interest in participating. I planned to use a snowballing technique in case I could not recruit the desired number of participants through the initial approach to recruitment, in which the participants who came from the self-selection method were asked to refer people they knew who met the criteria for participation in the research.

Parents' selection procedure

To approach the parents of children with disabilities whose children were in schools, I contacted the head teachers of the three selected schools. I briefly introduced the aims, processes and intended outcomes of the research. The head teachers were asked to provide the recruitment materials, which contained the introduction letter, information sheet and consent form, all translated into Nepali, to all parents of children with disabilities studying in their schools (examples of introduction letter, information sheet and consent form used are given in Appendices B, C and D respectively). The parents who were not literate were asked to seek support from literate family members or neighbours to read these materials. It is quite common in Nepal to seek such support from others in their neighbourhood when they need to read documents from government offices, or letters from their family members residing abroad at the time when telephones were not common. In this way, parents were ensured of access to the recruitment materials.

The parents were provided with sufficient time to review the information, and then invited to contact me if they wished to have any additional clarification. The recruitment materials included my contact information. Parents interested in participating in the research were invited to contact me directly by phone. As I had not met any of the parents before and my recruitment materials had clearly articulated the voluntary nature, benefits and risks of participation, there was no coercion regarding their participation? Similarly, the issue of conflict of interest was addressed by distributing the recruitment materials to all eligible participants and by inviting interested parents to contact me directly.

Volunteers from the parent group were requested to pass the recruitment materials on to other potential parents interested in taking part in the research. These volunteer parents contacted potential participants, informed them about the research, and provided them with the recruitment materials and my contact information.

Parents' background

Altogether nineteen parents of children with disabilities participated in the interviews. While 10 parents were selected through self-selection, the other nine came from a snowballing approach. Table 3.1 presents background details for all parent participants. All the identifying information such as names of participants and places has been changed for confidentiality as widely practised in qualitative research (see for example, Dudley 2017).

Table 3.1: Detailed background of interview participants

Participant 1	
General information:	Daya, female, age range 30–40, mother of a boy with hearing impairment
Origin/ethnicity/caste:	Hill, Janajati, minority
Education/occupation:	Primary level, housewife
Interview venue/date/length:	Schoolground; 20/02/2017, 56:49 minutes
Child information:	Rabin, boy, 8, hearing impairment (profound)

Siblings:	Second of two brothers
Schooling information:	Enrolled in School A for last two years
Participant 2	
General information:	Jamuna, female, age range 30–40, mother of a girl with hearing impairment
Origin/ethnicity/caste:	Plains, indigenous, minority
Education/occupation:	None, housewife
Interview venue/date/length:	School room; 21/02/2017, 45:44 minutes
Child information:	Rubina, girl, 9, hearing impairment (profound)
Siblings:	First of two siblings
Schooling information:	Enrolled in School A for last two years
Participant 3	
General information:	Choudhary, male, age range 40–50, father of a girl with hearing impairment
Origin/ethnicity/caste:	Plains, indigenous, minority
Education/occupation:	Primary, farmer
Interview venue/date/length:	Schoolground; 21/02/2017, 46:38 minutes
Child information:	Asmita, girl, 14, hearing impairment (profound)
Siblings:	Second of four siblings
Schooling information:	Enrolled in School A for last three years
Participant 4	
General information:	Prakash, male, age range 40–50, father of a boy with hearing impairment
Origin/ethnicity/caste:	Plains, indigenous, minority
Education/occupation:	Primary, farmer
Interview venue/date/length:	Schoolground; 23/02/2017, 42:22 minutes
Child information:	Dipesh, boy, 14, hearing impairment (profound)
Siblings:	First of two siblings
Schooling information:	Enrolled in School A for last three years
Participant 5	
General information:	Miya, male, age range 30–40, brother-in-law of a boy with hearing impairment
Origin/ethnicity/caste:	Hill/minority, Muslim, minority group
Education/occupation:	Secondary, farmer
Interview venue/date/length:	Schoolground; 23/02/2017, 44.06 minutes
Child information:	Anish, boy, 15, hearing impairment (profound)
Siblings:	Second of three siblings
Schooling information:	Enrolled in School A for last two years
Participant 6	
General information:	Anish, male, age range 20–30, brother of a girl with visual impairment
Origin/ethnicity/caste:	Plains, indigenous, minority
Education/occupation:	Bachelor’s degree, student and journalist
Interview venue/date/length:	Hostel room; 22/02/2017, 51:38 minutes
Child information:	Susma, girl, 12, visual impairment (profound)
Siblings:	Second of three siblings
Schooling information:	Enrolled in School B for last four years
Participant 7	
General information:	Karuna, female, age range 30-–40, mother of a girl with visual impairment

Origin/ethnicity/caste:	Hill, Brahmin, majority
Education/occupation:	Primary, housewife
Interview venue/date/length:	Hostel room; 22/02/2017, 38:56 minutes
Child information:	Sabina, girl, 8, visual impairment (profound)
Siblings:	First of three siblings
Schooling information:	Enrolled in School B last year
Participant 8	
General information:	Tiru, female, age range 50–60, grandmother (maternal side) of a boy with visual impairment
Origin/ethnicity/caste:	Hill, Brahmin, majority
Education/occupation:	None, housewife, owns a moving shop (*thela gadi*)
Interview venue/date/length:	Hostel room; 22/02/2017, 38:56 minutes
Child information:	Saput, boy, 6, visual impairment (profound)
Siblings:	Only child, lives in the maternal home, parents separated
Schooling information:	Enrolled in School B last year
Participant 9	
General information:	Narayan, male, age range 50–60, father of a boy with visual impairment (the child also occasionally contributed to the conversatin)
Origin/ethnicity/caste:	Plains, indigenous, minority
Education/occupation:	Bachelor’s degree, runs a small pharmacy shop
Interview venue/date/length:	Hostel room; 22/03/2017, 41:54 minutes
Child information:	Ayush, boy, 14, visual impairment (profound)
Siblings:	Second of three siblings
Schooling information:	Enrolled in School B for last three years
Participant 10	
General information:	Shivani, female, age range 60–70, grandmother of a girl with intellectual disability (this was a family interview and the aunt and uncle of the child also contributed to the interview)
Origin/ethnicity/caste:	Hill, Chhetri, majority
Education/occupation:	None, housewife
Interview venue/date/length:	Her home; 14/03/2017, 26:29 minutes
Child information:	Suriti, girl, 19, intellectual disability
Siblings:	Only child (father died, and mother re-married and moved to her new house)
Schooling information:	Had a few years of schooling in School C, but dropped out three years ago
Participant 11	
General information:	Hari, male, age range 50–60, grandfather of a boy with intellectual disability (this was a family interview and the grandmother of the child also contributed to the interview)
Origin/ethnicity/caste:	Hill, Brahmin, majority
Education/occupation:	Primary, farmer
Interview venue/date/length:	Their home; 18/03/2017, 52:41 minutes
Child information:	Samir, boy, 8, intellectual disability
Siblings:	First of three siblings
Schooling information:	Enrolled in School C for last 9 months
Participant 12	

General information: Kushal, female, age range 50–60, mother of a girl with Down syndrome
Origin/ethnicity/caste: Hill, Brahmin, majority
Education/occupation: None, housewife
Interview venue/date/length: Their home; 18/03/2017, 52:42 minutes
Child information: Gayathri, girl, 20, intellectual disability (Down syndrome)
Siblings: Third of three siblings
Schooling information: Enrolled in School C four years ago

Participant 13

General information: Sarita, female, age range 20–30, single parent of a girl with disabilities
Origin/ethnicity/caste: Hill, Brahmin, majority
Education/occupation: None, housewife, house cleaner
Interview venue/date/length: Her workplace; 24/02/2017, 41:04 minutes
Child information: Prapti, girl, 5, unidentified (multiple)
Siblings: Only child, father left her and her mother
Schooling information: Enrolled in a private school last year

Participant 14

General information: Sheetal, female, widow, age range 30–40, mother of a boy with disabilities
Origin/ethnicity/caste: Hill, Brahmin, majority
Education/occupation: Primary, works as a support staff in a bank
Interview venue/date/length: Her home; 25/03/2017, 59:44 minutes
Child information: Buddhi, boy, 12, cerebral palsy (multiple)
Siblings: Second of two brothers, father died
Schooling information: Never enrolled, schools denied enrolment because he is not able to go to the toilet by himself

Participant 15

General information: Bel Bahadur, age range 60–70, father of a man with a visual impairment (this was a family interview; mother, sister-in-law and the man with a disability himself contributed to the interview)
Origin/ethnicity/caste: Hill, Brahmin, majority
Education/occupation: None, farmer
Interview venue/date/length: Their home; 18/02/2017, 37:17 minutes; + 14/03/2017; 59:29 minutes
Child information: Padam, man, 30, visual impairment (profound)
Siblings: First of two brothers
Schooling information: Enrolled in a mainstream school and did his primary schooling, then was expelled from the school because of his disability

Participant 16

General information: Tulia, female, age range 30–40, mother of a boy with multiple disabilities
Origin/ethnicity/caste: Plains, majority group
Education/occupation: None, run a small business from their home
Interview venue/date/length: Her home; 17/03/2017, 33:17 minutes
Child information: Ritesh, boy, 5, cerebral palsy, polio (multiple)
Siblings: Second of three brothers
Schooling information: Never enrolled because of severe condition

Participant 17

General information:	Biswa, male, age range 50–60, father of a boy with intellectual disability (this was a family interview and child's mother also contributed to the interview)
Origin/ethnicity/caste:	Hill, Brahmin, majority
Education/occupation:	Primary, politics
Interview venue/date/length:	Their home; 19/03/2017, 31:59 minutes
Child information:	Bigul, boy, 19, intellectual disability
Siblings:	First of four siblings
Schooling information:	Enrolled in a mainstream school but dropped out as he could not pass the high school exams
Participant 18	
General information:	Pawan, male, age range 40–50, father of a boy with multiple disabilities (this was a telephone interview)
Origin/ethnicity/caste:	Hill, Brahmin, majority
Education/occupation:	Bachelor's degree, government job
Interview venue/date/length:	Telephone conversation; 16/04/2017, 30:09 minutes
Child information:	Jagat, boy, 15, cerebral palsy, intellectual, multiple
Siblings:	Second of three siblings
Schooling information:	Never enrolled in school because of severe condition
Participant 19	
General information:	Ritu, female, age range 20–30, mother of a boy with intellectual disability
Origin/ethnicity/caste:	Hill, Brahmin, majority
Education/occupation:	High school, housewife, owns a moving shop (*thela gadi*)
Interview venue/date/length:	Her workplace; 13/04/2017, 40:49 minutes
Child information:	Bibek, boy, 9, intellectual disability
Siblings:	First of two brothers
Schooling information:	Enrolled in an integrated school for last two years

The information above is summarised in Table 3.2 to present an overview of the demographic characteristics of the parents. There were more female than male participants. In some cases, the family members of children with disabilities other than their fathers and mothers took part in the interviews, for example three grandparents, one brother and one brother-in-law. Similarly, more parents of boys than girl children participated in the interviews. Among the participants there were six parents of non-school-attending children; three of these children had dropped out of schools and three had never been enrolled. Parents were interviewed in familiar surroundings such as at home (7 parents), their workplace (2 parents), school/hostel (9 parents), and also one interview over the telephone.

Table 3.2: Demographic characteristics of interview participants

Characteristics	Numbers of participants
Total parents interviewed	19

Parents' gender	Female -> 10; Male -> 9
Parents' age group	20–30 -> 2; 30–40 -> 6; 40–50 -> 4; 50–60 -> 5; 60–70 -> 2
Parents' literacy level	Literate -> 14; Illiterate -> 5
Parents' origin	Hill -> 13; Plains/Terai -> 6
Religious background	Hindu -> 18; Muslim -> 1
Participants' disability status	With disability -> 1; Without disability -> 18
Caste/ethnicity background	Brahmin/Chhetri hill -> 11; Janjati hill -> 2; Janjati Terai -> 4; Dalit Terai -> 2
Employment status	Self-employed -> 5; Causal employment -> 6; Government service -> 1; Unemployed ->7
Place of interview	Home -> 7; Work -> 2; School/hostel -> 9; Telephone -> 1
Family/individual interview	Family interview -> 4; Individual interview -> 15
Participants' relationship to children with disabilities	Grandmother -> 2; Mother -> 8; Grandfather -> 1; Father -> 6; Brother -> 1; Brother-in-law -> 1
Gender of children	Girls -> 7; Boys -> 12
Children's disability	Hearing -> 5; Sight -> 5; Intellectual -> 5; Multiple -> 4
Children's age group	5–10 -> 8; 10–15 -> 5; 15–20 -> 5; 20+ -> 1
Children's schooling status	School attending -> 13 (residential -> 10 and non-residential -> 3; government school -> 12 and private school -> 1; special school -> 12 and regular school -> 1); School non-attending -> 6 (dropped out -> 3 and never-enrolled -> 3)

Professionals' selection procedure

To invite professionals and committee members to participate in focus group discussions, the head teachers were asked to distribute my recruitment materials to all teachers, and members of school management committees and parent–teacher associations. The participants were provided with information about the research and the voluntary nature of participation. The participants had enough time for queries and clarification via phone. Those who showed interest were invited to join the focus group discussions. Similarly, to reach out to government officials at the District Education Office such as under-secretaries, school supervisors, the head of the assessment centre and resource persons, I contacted the District Education Officer and requested that he distribute my recruitment materials during periodic meetings at the office. The participants who were interested in taking part in the focus group discussions were also invited to contact me via phone. The officials from the municipal council office were similarly contacted through the head of the institution and interested officials were invited to take part in focus group discussions.

Professionals' background

Altogether 23 professionals took part in focus group discussions. Professionals were invited to join one of four different groups (teachers; head teachers; community members; and government officials). The teachers' group included six teachers (three resource teachers and three mainstream teachers; of those, four participants were male and two female). Three of these participants were teachers with disabilities (one with sight, one with hearing and one with a walking disability). The head teachers' group included six persons in leadership positions from the three schools. In this group, all participants were male. One participant was the outgoing (former) head teacher of one of the schools.

The third group was community members who represented the school management committees or parent–teacher associations of the schools selected. Initially, I had a target of six participants from the three schools for this group, but only three members – all from the same school – showed interest and took part in the discussion. In this group, two participants were male, and one was female.

The last group was government officials. In this group, eight participants took part; two under-secretaries and one school supervisor from the District Education Office; two resource persons from the resource centres,[14] the coordinator of the assessment centre, one local level trainer of teachers and one official from the local council office (the newly formed municipality). The participants were all male and one participant in this group was a person with physical disability. All focus group discussions were held in a quiet room, provided by a local electronics shop. It was a room above the shop, which was used to store goods. It had enough sofas, chairs and tables for the participants. Table 3.3 provides background information for each of the focus group participants. The names of participants and their affiliated institutions have been changed to maintain confidentiality.

Table 3.3: Background information of focus group participants

Focus Group 1 - Teachers' group (total participants: 6, female 2, male 4; discussion date: 29/03/2017; discussion time: 100:47 minutes)					
Code	**Participant name**	**Gender**	**Title**	**Affiliation**	**Remarks**
R1	Champak	Male	Special class teacher (for students with hearing disabilities)	School A	Teacher with a hearing disability, was supported by an interpreter
R2	Dambar	Male	Special class teacher (for students with hearing disability)	School A	Teacher with a walking disability
R3	Laxu	Female	Mainstream teacher	School A	

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[14] A resource centre is a sub-district level wing of the District Education Office, responsible for overseeing and supporting school functions and training of the teachers within their defined catchment area.

R4	Dhundi	Male	Special class teacher (for students with visual disability)	School B	Teacher with a visual disability
R5	Rakesh	Male	Special class teacher (for students with intellectual disability)	School C	
R6	Leela	Female	Mainstream teacher	School C	

Focus group 2 - Head teachers' group (total participants: 6, female 0, male 6; discussion date: 30/03/2017; discussion time: 119:56 minutes)

Code	Participant name	Gender	Title	Affiliation	Remarks
R7	Resham	Male	Head teacher	School A	
R8	Harish	Male	Assistant head teacher	School A	
R9	Bhumi	Male	Head teacher	School B	
R10	Shah	Male	Assistant head teacher	School B	
R11	Bhadra	Male	Head teacher	School C	
R12	Sukdev	Male	Former head teacher	School C	

Focus group 3 - Community members' group (total participants: 3, female 1, male 2; discussion date: 04/04/2017; discussion time: 69:19 minutes)

Code	Participant name	Gender	Title	Affiliation	Remarks
R13	Bhakta	Male	Chairperson, School Management Committee	School A	
R14	Anup	Male	Chairperson, Parent–Teacher Association	School A	
R15	Mithu	Female	Member, School Management Committee	School A	

Focus group 4 - Government officials' group (total participants: 8, female 0, male 8; discussion date: 05/04/2017; discussion time: 82:14 minutes)

Code	Participant name	Gender	Title	Affiliation	Remarks
R16	Babuhari	Male	Undersecretary	Education Office	
R17	Mani	Male	Section Officer	Municipality	
R18	Kaviram	Male	Resource Person	Resource Centre A	
R19	Jayram	Male	Resource Person	Resource Centre B	
R20	Mit	Male	Teacher trainer/local activist	Kapilvastu	Participant with a walking disability
R21	Arun	Male	School Supervisor	Kapilvastu	
R22	Bansi	Male	Coordinator	Assessment Centre	

R23	Ravi	Male	Undersecretary	Education Office	Separate discussion[15]

3.3.4 Language and recording conversations

The interviews and focus group discussions were held in the participants' mother tongue Nepali (except one interview, with participant 2, which was conducted in Bhojpuri). All conversations and discussions were audio-recorded (using Olympus Digital Voice recorder WS-853) after receiving written permission from the participants. Two copies of the written consent[16] (one for the participant and one for the researcher) were obtained from each of the participants before audio-recording. The form used to obtain participant consent including its Nepali translation is provided in Appendix D. The conversations with parents lasted from 30 minutes to 97 minutes, while the focus group discussions lasted from 70 to 120 minutes.

3.3.5 Data-gathering process

Interviews in the form of informal conversations with the parents of children with disabilities and focus group discussions with professionals were the primary sources of data for this research. During data collection, parents and professionals were encouraged to share their experiences and insights so that a broad range of data associated with their experiences in raising and educating children with disabilities could be gathered. In addition to these informal interview conversations and focus group discussions, documents and a research journal also contributed to my data. Although the findings drew heavily upon the data collected through interviews and focus group discussions, document analysis and the research journal complemented those data. The interview and focus group guidelines with their Nepali translation used for the data collection are provided in Appendices E and F respectively.

Interviews in the form of informal conversations

Informal interviews were conducted with the parents and other family members of children with disabilities. These interviews took the form of informal conversations in this research. A conversational form of interview helped parents express their feelings, sorrows and moments of joy in raising and educating their children more naturally. Moreover, these conversations allowed flexibility and adjustment to incorporate participants' views as per contextual needs. As expressed

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[15] Ravi was supposed to attend the focus group discussion. However, as he could not make it due to his busy schedule and as he was keen to discuss the issues around special education in the district, he invited me to talk to him at his home. Therefore, I went to his home one morning on 15/04/2017 and chatted for 82:14 minutes.

[16] Except for one interview participant, from whom I obtained oral consent because the interview was done by phone.

by many of the participants, it was the first opportunity they had had to speak up or to raise their voices and concerns. As such, the interviews adopted an open and relaxed environment.

Moreover, the informal nature of the interviews in this research allowed to me delve into the experiences and understandings of parents and other family members of children with disabilities. They were asked, through open-ended questions and prompts, to elicit their experiences/stories about raising their children; their choices (or lack of choices) about schooling options for their children; and their experiences about engagement with the school.

Vignette-based focus group discussions

The use of focus group discussion in this research was guided by a desire to obtain differing perspectives from professionals and community members about schooling options for children with disabilities and parental engagement in their children's schooling. The use of focus group discussions in qualitative researches including those related to inclusive education is widespread. Elizabeth Altieri, for example, chooses focus group discussion as a data-gathering tool in her qualitative research that aims at exploring experiences of teachers in the context of inclusive education. In Altieri's research, focus group discussions provided participants with a space for 'their voices in solo and in dialogue with others' and allowed the researcher to observe and note 'the unfolding contradictions and complexities' that expand our understanding of the topic (Altieri, 2001, p. ii). Liamputtong (2007) thinks that 'because the goal of a focus group is to give opportunities for an interactive exchange of opinions, it is less influenced by the researcher' (p. 106). Similarly, Freidus (2002) links focus group data with the narrative approach in that focus groups gather 'a wide range of stories: stories of practice, stories of context … stories of dreams and goals' (p. 160). Further, focus groups are important as the re-occurrence of themes in the focus group data provides an additional insight for the analysis.

In this research, focus group discussions were based on vignettes. Vignettes are exemplar cases that stimulate and engage participants actively to express their experiences and views (Armstrong, Price, & Crowley, 2015). Vignettes, according to Armstrong et al. (2015), allow researchers to explore 'decision-making behaviours and attitudes about an issue' (p. 385). After conducting interviews with parents, drawing on their stories, three vignettes were drafted describing different scenarios of parental experiences of raising and schooling or non-schooling of children with disabilities. The vignettes were then presented in a sequence during all focus group discussions followed by a set of open-ended questions. One of the vignettes and the sample questions used with vignettes are presented in the box below (also see Appendix F for all three vignettes). Through these interactive vignettes, the participants could relate the contexts with their own experiences and situations. The use of vignettes also helped focus group participants to entirely and seriously engage in the discussion.

An example of a vignette used in the focus group discussions

Asmita is 17 years old now. She cannot speak and is not able to learn as per the level of her peers. She likes to listen to music. Her family migrated to this place three years ago. Her parents were sending Asmita to a school near their old place. But when they migrated here, it took one year for them to learn that there is a school in their locality which can cater for the needs of children like their daughter Asmita. Asmita started attending the school two years ago. Laxmi, her mother, when asked to tell her experiences about her engagement in school activities, said, 'I would go to the school in the morning to leave her and in the afternoon to bring her home. Sometimes I would also let her follow her peers to the school.' She added, 'I would meet the caretaker sometimes; and once, Asmita's teacher also asked me to visit him.' However, in Asmita's previous school (abroad), parents would be invited to visit the school regularly. All parents were taught how to help the children brush their teeth, take a shower and trim their nails. Therefore, Asmita is able to do these things by herself. She added that, 'if the current school had invited me, I would have been able to explain to the other parents how we parents can help our children do these things at home'.

Questions for focus group discussion:

What is your response to the story?
According to your view, what would parents think of this situation?
How would you support a family like this?
What do you do in this school to ensure high quality parental engagement?
What possibilities are there to engage such parents in your school?

Documents and reflective journal

The documents collected from the schools and the research journal complemented the data sources. The documents gathered during the field visit included school documents such as schools' code of conduct, citizen charter, magazines, decisions and plans. In those documents, I sought information related to parental engagement especially relating to special needs education. In addition, I collected related documents from central departments.

I also used a journal to take notes of interesting events, reflections, insights and subjective impressions while I was in the field. The journal assisted me to take note of non verbal aspects, settings, subtleties and nuances and reflect back, later during the data analysis phase, to articulate the stories I heard from the participants, as in the Perry's (2017) example of the use of a field diary that helped her to capture the nuances of voice, relations, appearances and settings, which were not captured on audio recordings. This aligns with the approach taken in this research to incorporate different ways of knowing and folk wisdom.

Overall, my data collection procedures were flexible. This flexibility offered me an opportunity to make adjustments in my initial plan as were necessary in the field. I used four different tools, namely, interviews, focus group discussion, documents and reflective journal to collect data; each data set complemented the others at the analysis phase, although interview conversations and focus group discussions were the major data sources.

3.3.6 Data analysis

The whole data analysis process adopted in this research is shown in Figure 3.1. As shown in this Figure, I commenced data analysis by first transcribing the audio-taped conversations and focus group data in Nepali and then translating those transcriptions into English. Initial analysis was made during this phase, by seeking some critical instances in the stories of parents and professionals to be used in the later stage of analysis. Following this, I began to construct case-focused narratives in the form of portrayals of selected participants, which I present in Chapter 4.

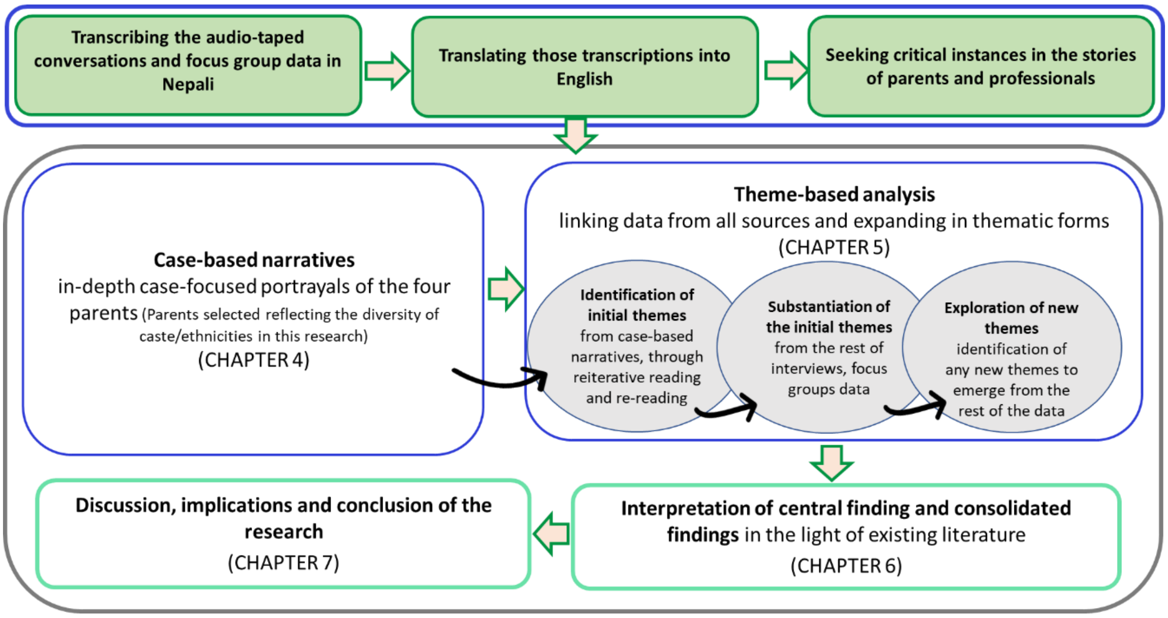

Figure 3.1: Flowchart showing data analysis process

For this, four parents were chosen to represent the different caste and ethnic backgrounds of the participants (as detailed in Chapter 4). The following account made by Fritz (2008) was found to be useful to form case-focused narrative portrayals in this research:

> begin with context of the case, … write a rich, thick description of the case … – what happened, who were the actors, what was their interaction; … If it’s a person, who is it? What is their background, history? What information is to be analysed? (p. 5)

Following the construction of the case-focused narrative portrayals, I undertook thematic analysis. This is in line with Fritz’s (2008) view that theme-based analysis should follow the case-based narratives. For the thematic analysis, as shown in the box on the right containing three circles in

Figure 3.1, first, I coded and analysed the four in-depth narrative portrayals to identify the initial themes, from which I obtained 14 themes. Secondly, I analysed the remaining data (the transcripts of 15 parent interviews, four focus group discussions, documents and the research journal) with a view to substantiate the initial themes identified in the first phase. Thirdly, I also carefully looked for any new themes that might emerge. Five new themes emerged at this stage. All the themes thus identified are presented in the first part of Chapter 5 along with supporting quotations from the research participants. Each theme is then expanded in the second part of Chapter 5, which finally led me to conclude with a central key finding and a set of consolidated findings of the research.

In essence, data analysis was done at two levels in this research using case-based narrative and thematic techniques. Drawing on the works of relational researchers such as Finlay and Evans (2009), narrative researchers such as Riessman (2008) and qualitative researchers such as Ayres et al. (2003), these two techniques were viewed as being most appropriate for this research. A similar combination of case-based and theme-based approaches to data analysis was used by Xiaoxia Chen in her doctoral research focusing on the parenting experiences of Chinese immigrant parents in the United States and draws on what she describes as 'case-focused narrative analysis' and 'cross-case thematic analysis' (Chen, 2013, pp. 52-54). Chen references Williams (1984) in her presentation of case-focused narratives as portrayals that convey what is significant about individual immigrant parents' experiences of educating their children, rather than representative cases in any statistical sense.With regard to cross-case thematic analysis, she quotes Webster and Mertova (2007)'s focus on 'highlighting and capturing of critical events contained in stories of experience' (p. 52). Similarly, in her doctoral research aimed at understanding the lived experiences of Latino parents of children with disabilities, Cheryl Takemoto presents and analyses her field data in the form of selected participant profiles, detailed narratives of selected parents and 'cross-case findings', drawing on the common patterns found in the stories of different parents (Takemoto, 2016, pp.38-40).

The participants' individual narrative accounts are unique and exclusive to their contexts, and as such are significant in themselves. Hence case-based narratives, in the form of portrayals, were used in this research. According to Finlay and Evans (2009), the relational researcher constructs case-focused narrative portrayals to present the 'particular life events' or experiences of participants chronologically as revealed by participants (p. 146). These narratives 'offer a way into individual's life stories in all their particularity and richness' (Finlay & Evans, 2009, p. 146). They are important for understanding the context in which participants experience the events, as they draw on their own words and how they attempt to construct their reality. However, at this stage, as suggested by Finlay and Evans (2009), care is needed to 'distinguish between living a life story, telling and reliving that life story and retelling that life story' (p. 149). During this phase, the researcher also begins the thematic analysis of the data in which he/she identifies relevant texts for quotations, or 'themes, scripts and metaphors' to be taken up for the next phase of data analysis – thematic analysis (p. 146).

While narratives need to be grounded in participants' words and to draw on their voices to reflect individuals' reality, general issues that are common to all respondents' accounts are also of importance for data analysis. These can be addressed by theme-based data analysis (Finlay & Evans, 2009; Riessman, 2001a). Theme-based analysis aims to describe the important patterns identified in the data (Finlay & Evans, 2009). Theme-based analysis focuses on the content of the stories to identify common issues or themes across participants' narratives (Riessman, 2008). As themes have to emerge from the data, there is a need to spend a considerable amount of time and space for themes to take their final shape. According to Finlay and Evans (2009), 'mostly, meanings have to be searched for and themes shaped up painstakingly in successive iterations' (p. 150). They also suggest that the relational researcher needs to be careful to offer 'general themes' that could capture the accounts of all participants, otherwise it is likely that themes may reflect some participants' experiences more strongly than others.

As data analysis is a reiterative process, it was not as linear as shown in Figure 3.1. Rather, it required many iterations in the form of close reading of the texts, sorting/sifting, pattern seeking, and re-reading, grouping and regrouping of texts and themes, with a view to finally making meaningful and coherent narratives for the audience. In the narrative approach, not only what is told is important, but also how the story was told, including the sequencing, specific words or metaphors chosen by a particular participant, and the contexts (who tells about whom, where and in what situation) or broader social contexts in which these narratives were told (Riessman, 2001b). Therefore, during the data analysis, my focus was not only on doing a close reading of texts or just looking at the content of the plain language in the stories, but also on exploring why participants chose those specific stories and events, and the ways they told the stories.

Analysis involved a series of other tasks: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (as described by Braun & Clarke, as cited in Finlay & Evans, 2009, p. 150). While reading and re-reading transcripts of all types of data and grouping and regrouping themes to identify the patterns and codes in the texts, I used paper margin coding, colour coding and in-text coding (Saldaña, 2009, 2015; see also Creswell, 2012). The codes were then clustered to generate common themes. Mind mapping (Buzan, 2005) was used to generate unique (non-overlapping) themes, and to ensure a natural flow across the themes generated. I also used NVivo software (installed from the Flinders

University portal) to organise and store all my data. While most of the coding and theme-generating tasks were done manually, NVivo assisted me in organising and storing the data in a single platform in an easily retrievable format.

Moreover, a story map is used in Chapter 6 to present the key finding and consolidated findings that emerged from this research, followed by their interpretation in the light of relevant literature. The use of a story map was also found to be aligned with the narrative approach employed for data analysis in this research. Although story maps are an effective teaching and learning tool, the growing use of this technique in research studies as an analysis tool is evident (Li, 2000; Reutzel, 1985; Ureda et al., 2011). According to Li (2000), 'A story map is a graphic display of the structure of a story and its parts' (p. 11). It provides readers with 'a bird's eye view of the basic story structure and the relationship between story elements' (p. 42). Ureda et al. (2011) suggest using story maps to encourage people to participate actively in dialogue. Story maps can also involve 'aesthetic attunement to data and visual representation' (Lapum et al., 2015, p. 1). As such, a story map was found to be an important tool to demonstrate the findings in this research. Following the interpretations of findings in Chapter 6, discussion, implications, suggested recommendations, reflections and conclusion of the research are presented in Chapter 7.

3.3.7 Ethical issues

While ethics protocols and guidelines about ethical conduct for researchers outline certain principles (such as respect, protection, informed consent, non-deceptiveness, right to knowledge of research outcome, confidentiality and privacy) along with the ways to act upon them; when we actually enter the field, they are not so straightforward, as we have to face a myriad of challenges and uncertainties (Finlay & Evans, 2009). Finlay and Evans (2009) suggest that relational researchers should act not only from their minds but also from their hearts and call for researchers to acknowledge their interpersonal bonds with participants and to take responsibility for their actions and their outcomes. The concern about ethics in relational research is therefore much more than just following the rules and procedures. Liamputtong's (2007) quotation from Smith's (2005, p. 96) work equally highlights this line of argument: 'Research ethics is often much more about institutional and professional regulations and codes of conduct than it is about the needs, aspirations, or worldviews of "marginalized and vulnerable" communities' (p. 23).

Researchers therefore need to be attentive to safeguard their participants' dignity, interests and voices at every stage of the research process: pre-research, data gathering, data analysis and research concluding phase (Finlay & Evans, 2009). As relational researchers, Finlay and Evans (2009) state, ‘we are called upon to be reflexive about our role as researcher at every stage of the research and to critically examine the impact of any imbalances of power that may arise’ (pp. 159–160). For relational researcher, the relationship with research participants is an important aspect of research ethics, which calls for a ‘move towards more collaborative, egalitarian, open relationships as opposed to exploitative, instrumental ones’ (Finlay & Evans, 2009, p. 160). For Liamputtong (2007) researching vulnerable groups of people is different from researching other groups of people and therefore ‘extreme sensitivity is needed in the conduct of research’ (p. 6).

The above-mentioned considerations of research ethics for relational research guided the different stages of this research, from approaching the research site, recruiting and meeting participants, eliciting data from them, and analysing the data. The voluntary nature of participation and the ability to withdraw from participation for any reason at any time without any negative consequences was emphasised to the participants in advance. The information pack provided to each participant explicitly articulated the research objectives, participation process and reporting procedures, with a view to ensure transparency and the rights of the participants to be informed of the research process. Participants were encouraged to bring someone with them for support, and also they were informed that they were free to opt for a break, reschedule, or to no longer be involved whenever they felt the need. In addition, I collected information related to local health/counselling services to link participants with such services if it was required, but fortunately that was not the case during my field work. Assigning a pseudonym to each participant and each school and removing any other identifying information ensured the privacy and confidentiality of participants. After the field work, all materials from the field were secured in a locked filing cabinet and password-protected computer folders. Records and transcriptions will be destroyed after a certain period after the completion of this research as per the protocol of the university.

In addition, I followed the protocol of the Social and Behavioural Research Ethics Committee of Flinders University to ensure the ethical standards of this research. I complied with all institutional procedures and received ethics approval from the Ethics Committee in January 2017 (Appendix G). I found this protocol to be exemplary, as it has not only incorporated all the principles stated above, but also detailed various practical issues and procedural aspects that I might come across at each stage of the research. As such compliance with it was itself a rigorous process. In Nepal, the education sector does not require any formal ethics approval. Although not mandatory for this research, I consulted the Nepal health sector’s guidelines for ethical compliance (Ministry of Health and Population [MoHP], 2011), which encompasses universal principles (respect for human beings, protection, research merit and integrity, justice, beneficence, transparency and reflexivity) that are often highlighted by documents from other countries such as the Australian National Statement on Ethical Conduct (National Health and Medical Research Council, Australian Research Council and Australian Vice Chancellors' Committee, 2015). Furthermore, the organisational procedure of obtaining written permission from school head teachers to enter the school sites before commencing the field work was complied with (see Appendix H).

3.4 Chapter summary

This chapter has focused on the methodological choices taken to support this research exploring the experiences and insights of participants in relation to raising and educating children with disabilities. A qualitative approach to research was employed in this research as it is useful when the aim is to elicit nuanced data that comprise subjective experiences and insights. A qualitative approach was also helpful in accessing hard-to-reach people in their natural settings without imposing any artificiality in their day-to-day life; and to explore their concerns and bring them to the fore. Moreover, relational-centred research was employed to explore people's interactions or their intricately linked relationships with other people or contexts. Relational research promises to make such complex matters comprehensible. Relational research also informed the decisions at various stages of this research from data gathering, accessing the research site, establishing relationships with the participants to eliciting their experiences and insights. In addition, the narrative approach, as a bottom-up approach that is rooted in people's daily life, served as a participant-friendly tool for data reporting, presentation, analysis and interpretation. In the next chapter I provide four case-focused portrayals of selected participants.

CHAPTER 4 - CASE-FOCUSED PORTRAYALS: THE UNIQUE EXPERIENCES OF PARENTS OF DIVERSE ETHNIC/CASTE BACKGROUNDS IN NEPAL

> **Going with the flow:** An old man accidentally fell into the river rapids leading to a high and dangerous waterfall. Onlookers feared for his life. Miraculously, he came out alive and unharmed downstream at the bottom of the falls. People asked him how he managed to survive. 'I accommodated myself to the water, not the water to me. Without thinking, I allowed myself to be shaped by it. Plunging into the swirl, I came out with the swirl. This is how I survived.' (A Taoist story)[17]

4.1 Chapter introduction

This chapter presents portrayals of four parents selected from the total of 19 parents interviewed in this research. The portrayals highlight experiences of the selected parents of living with their children with disabilities, in which they were involved in their care, upbringing, health and schooling. Although the stories of all parents interviewed for this study were equally important, valid and valued, only four of these are selected for this chapter to reflect the different ethnic, caste, language and cultural backgrounds of the participants as well as the types and categories of disabilities of their children (See Tables 3.1 and 3.2). The names of the participants, their children, places and other identifying information in these portrayals have been altered to protect their identities.

The first portrayal is of Daya, from the *Newar* ethnic group, who was selected because she was representative of the many women in the Nepali context raising children, doing household chores and supporting a husband, who in this case works for a private transport company. Her younger son, Rabin, has a hearing impairment. The second portrayal is of Bel Bahadur, from the *Chhetri* caste group, which was chosen for its uniqueness as he was the father of Padam, a man aged 30 with a visual impairment, which did not appear until the age of nine. All family members including Padam, his mother and sister-in-law took part in the interview. The third portrayal is of Anish, from the *Tharu* ethnic group, who has a visual impairment, as did his sister Susma. Unlike in the other portrayals, Anish, the sibling of the child with disability, wished to participate in the informal interview. The final story is of Sheetal, from the *Brahmin* caste group, a woman whose son has severe cerebral palsy, and who was refused enrolment by the local school. The key themes emerging from these portrayals and from the rest of the field data are described in the next chapter.

In these portrayals, selected quotations and extracts of direct speech from the participants (with my questions or enquiries only on rare occasions) are included to recognise the importance of their

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[17] A Taoist story from *Zen stories to tell your neighbours* (p. 31) (Retrieved on 1 March 2019 from http://www.arvindguptatoys.com/arvindgupta/zen-for-neighbours.pdf).

voice. In addition, I have included contextual information to give the reader a full experience of the participants' lives and experiences. Data from the interview transcripts about events in their lives have been refashioned to form unfolding journeys in more chronological order than the stories the participants told (Clandinin, 2006). Each portrayal begins with some background, then I present the story itself and finally the conclusion. These four portrayals are linked by the inclusion of my own reflections as the researcher/interviewer reporting on what I heard, saw, observed or thought at the time of the conversation.

4.2 Daya

4.2.1 Background

It was a warm sunny morning in February. February is usually a relatively cold month in the western Terai (lowland) district of Nepal – my research site. I was waiting for Daya in the schoolyard in front of the school building. As it was my first interview, even though it would be in an informal style in keeping with a relational approach, I was both excited and a bit nervous as well. I was concerned about whether Daya would feel shy with me or get nervous during the conversation and not share much information. I was also very unsure as to how to initiate the interview and address the interview questions I had prepared on a sheet of paper. I was also thinking about what I should do during the interview – should I look at my sheet of paper to ask questions or should I just let it develop in a natural way? Will I forget to ask things I had in mind, if I choose not to read the questions? I decided to let the conversation flow naturally.

Daya had volunteered for the interview and had chosen the school as the meeting place. This school was about 18 kilometres from her house. Daya came at the agreed time, first meeting the *aaya* (caretaker staff at the school hostel).[18] The *aaya* brought Daya to where I was sitting and introduced me. Before starting our conversation, Daya told me she wanted me to meet her son and see his classroom. *Aaya* took her to the classroom and I followed. We stayed there for about half an hour. Then, Daya and I came back into the schoolyard, sat on the grass under the sun and began our conversation. Although in front of us, some 300 metres away, was a highway there was only an occasional movement of vehicles, which did not disturb our chat.

I began the conversation by extending my gratitude to Daya for agreeing to the interview. Daya told me that they were a small family of four with two sons. In search of a better life, her family moved from a hilly district to their current home in Terai some 10 years before. Her younger child, Rabin, 8,

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[18] An *aaya* or caretaker is a member of the school staff in integrated schools in Nepal; generally, a female hired on a temporary basis by the school to take care of the children with disabilities living in the hostel.

had a profound hearing impairment. She told me that her husband was a bus driver and hence was away most of the time. Daya said that she had the responsibility of taking care of her children and preparing them for school. She told me that they rented a one-room home from which she also sold goods such as books, pens, chocolates, biscuits and sweets to locals, which they stored in one corner of their home. Her husband bought many of the goods from an Indian market on his bus route, since this was a cheaper market for those kinds of goods.

4.2.2 Early childhood

Firstly, I asked Daya to tell me the story of her son from birth, including when and how she became aware that her son had a hearing impairment. She said:

> *He was 6 months old. On the day of bhat-khwai [a Hindu ritual when a child is fed with rice or solid food for the first time when he/she becomes 6 months old], we noticed that he was not feeling well. We took him to one of the hospitals in Butwal. Doctors in the hospital said, 'There is nothing wrong with him and nothing wrong will happen'. Therefore, we brought him back home. Then, at home, he suddenly became unconscious and closed his eyes. We took him to Butwal again to a children's hospital – Amda hospital. There, a doctor said, 'We will try a treatment, but your child cannot survive. He is going to die.' I cried. I believed that my son was not going to survive. Fortunately, after three days, he became conscious and after ten days we brought him back home. We started taking full care of him; we would stay with him all the time.*
>
> *At the time, it was hard for everyone to believe that my son would survive. As he was healing, we were hoping that one day he would speak. … We did not bother about his speaking until he became two because his brother also began to speak when he reached two. But when he did not speak then, we were suspicious. We took him to the hospital and the doctor confirmed that he had lost his hearing and would never speak. It was a great shock for us. … We took him to faith healers too. But he did not speak. Then after some time, we realised that he would be so forever. … He could not speak, but from time to time, he would try to utter some sounds; he would try to say ama and baba [mum and papa].*

Daya told me that the impairment was caused either by the anti-venom medication that she took for a snakebite when she was pregnant, or by meningitis. She added, 'if we had known that I had a baby in my womb, I would not have taken any medication'.

As we spoke I realised I was beginning to feel more relaxed and comfortable since Daya's mode of expression was so open and friendly. As she was from the *Newar* ethnic group, her mother tongue was not Nepali, yet she spoke Nepali very well. Daya was fluent and frank and I felt that she was honestly telling me about her experiences. She immediately responded to my questions and occasionally she would repeat her experiences to fill in the conversation. Next, I asked about her son's childhood. She recalled:

> *He was also very weak and could not walk. He started walking when he reached two and a half. He did not walk initially, that's why we used a walker. We helped him walk, massaged and helped do the physical exercise. It really gave us a big relief when we saw him walking.*

I also asked her about her experiences of visiting hospitals and the support she received there. She shared:

> *I took him to different hospitals in Butwal, but nothing improved. The doctor said, 'You may take him to Kathmandu and spend money, but it cannot be guaranteed that the treatment would be successful'. We were not able to spend a huge amount of money for his treatment. So we did not take him to Kathmandu. One of the doctors also suggested taking him to a hospital in Lucknow [an Indian city]. But we need to see our financial situation, don't we, sir?*

When asked about how her relatives and neighbours reacted when they came to know that Rabin was going to have this type of impairment forever or if they had any suggestions for his treatment, Daya replied that they might have had sympathy, but they did not have much idea about the problems her son had.

Then I asked if she had any interesting memories to share about bringing up her son. She said she felt sad when someone addressed a child with a disability by a label.

> *Some people call my son 'laato' [dumb]. I feel really bad. That hurts me. That really touches our heart. We feel bad when they say that. I wish people wouldn't address him that way. … Maybe because I have such experiences, if someone says something bad about her [the daughter of her neighbour who has intellectual disability]; it hurts me. I feel like people should not have talked like that. Only those who have such experiences, feel how difficult it is. They know the sufferings. Those who have not gone through such conditions do not know about it. Who would expect to have such a child initially? I went to various places and fulfilled the vows committed earlier. Initially I felt like this might be the result of all the sins that I might have committed in a past life, so I am cursed like this. I also scolded my husband. I said to him, 'You might have done something wrong, outside.'*

She went on to tell me that she went to different places for help. As time passed, she saw other mothers caring for their children and she felt like she was not the only one who was suffering:

> *I feel like I should be bold. Then I felt like if they can tolerate such sufferings, why not me? So, I don't feel very bad about him now. … I also saw other children, who were in fact in more difficult and complicated conditions than my son. That experience made me realise that I am not alone going through such sufferings. It made me stronger to face the reality.*

Daya was very open to sharing her experiences of raising and schooling her son. By this time, I had realised that the conversation was flowing very well. On two or three occasions, Daya talked non-stop for more than two minutes without any interruption by me; at such times, I just nodded my head. Sometimes, she was also seeking confirmation from me as well, by using tags such as 'don't we, sir?' I felt like she did not need to address me as 'sir'. However, as she spoke, I felt good because Daya was feeling comfortable talking to me. I felt like she was also feeling pleased to have this opportunity to share her stories, which she had not shared with others in such a detailed manner. Even though our conversation was taking a long time, I was keen to listen her experiences in detail. I felt she was also not concerned about the time. Therefore, I did not try to combine my questions and rush to conclude the conversation as I still needed to find out about her son's schooling, why she chose to send him to the school, how she explored different schools for him, and also her own experiences about engagement with her son's schools.

4.2.3 Schooling

In response to my question, 'When did you think about his schooling, and that he should study?' she said that she had an initial thought of not sending Rabin to school, but later she decided to enrol him. She added:

> *It is very difficult for mothers to keep their children away having such conditions. But what to do? For his future, I thought I have to compromise our love. I thought if he learns now, he would do something in future. He will become something. That is why we send him away from us. … He did not learn his sign language in his previous school. But in this school, he has learnt sign language. … Initially it was very hard for us to leave him in the school hostel. He also felt sad. On the very first day, I left him in the school and then went back. He cried a lot at the time of my departure. … Now he comes to school happily from home after school breaks. He says, 'I want to study in the school, this school is good'. He is aware of his condition. He knows, 'I am like this, and that is why I am here [in the hostel]'.*

Then I asked, 'How did you know about this school, and that this school offers teaching in sign language?' She said:

> *There was a camp in our place organised by an NGO. There I asked, 'I want to send my son to a school. What I should do?' Then one sister there said that she knows a teacher who teaches*

> *children like my son. She gave me a teacher's contact. He was a teacher from this school. I rang him. Then I came here to this school to visit him. However, I could not meet him here. He was out for training. Then later, I talked to him on the phone. He asked me to visit him at the school with my son. Then I came to the school. He asked different questions to Rabin. He also responded very well. … My son could not speak, but he knows many things because we gave him a variety of experiences. His father cannot spare much time for him. I am responsible for teaching him everything. Then the teacher said, 'He is good, we can teach him here.'*

When I asked her about her dreams for her son, she replied: 'Maybe he becomes a *thulo manchhe* [a great person]; and have a good future and do something.' Then I inquired: 'Like? (A long pause). Something specific? Have you got any thoughts about it?' She stopped for a while and said, 'Let us see. He should study first and become a *thulo manchhe*. And I wish that everything will go well.' When I asked how she felt about her son's school and hostel, she told me that she was proud of her child studying with other 'normal' children in the school.

> *The school activities are much better now. Students have been learning well since this new teacher came. My son's class was in a separate place before, but now they are brought quite near to the school. When these children stay with other 'normal' children then they learn much faster. Our children were not much experienced when they were there in the separate place. … Now they know about other friends. They learn many things. They are happy to be with other children. However, they are different in terms of their disabilities; but they are happy to see others. They feel happy in their heart.*

When I asked if she had any concerns or complaints about Rabin's school, she replied:

> *If the school promoted them to an upper grade, it would be nice. When people ask, 'In which grade does your child study?' I have nothing to tell them. It may be because there are only eight students with hearing impairment in this school. The school cannot keep them according to their achievement level. We, parents, wish our children to be kept in the proper grade. But how would school manage to put these students in separate grades? Maybe this is not possible. Apart from this, things are quite good now in the school.*

By now, I wanted to move to the question related to her experiences about working with the school. When I asked her how often she visited the school she replied:

> *Not very often. They have a two-month break from mid-June to mid-August. We would come to collect him before the break. Apart from this, I would come just if we want to take him home like on a Friday. Sometimes I feel like I am missing him a lot, then my husband would take him home if he happens to pass by this school. … Aaya madame also calls me from time*

> *to time. Last time she said, 'You come and see the school; now the school has done well; now they have their class upstairs. The new teacher has put up boards in the class.'*

She said when she comes to collect her son, she only meets the *aaya* and not the teachers and that she also speaks with the *aaya* on the phone from time to time, asking her, 'How is my son? What is he doing?' and so on. She told me that when she came to the school hostel, she would meet other children, and bring some candies and food for them. She emphasised, '*Aaya* madame is a very caring person.'

In response to my question about what she wants from the school for her son, Daya expressed her concern about the next school for her son:

> *The previous teacher was talking about his next school; he told me that he is going to arrange a school for Rabin for his upper grades in Chitwan or elsewhere. Now the previous teacher is in the process of going abroad.*

Then I asked how she would like to engage with school activities. She said that given her financial situation she may not be able to support the school financially, but she could help out in other ways by sweeping the classroom floor or staying with the children for a day at the weekend. She indicated she would appreciate the opportunity to sit with the head teacher, other teachers or the *aaya* and talk about the needs of her son. She also suggested that this could happen in a group and that if all parents came together and shared their knowledge that could make a difference:

> *If we come alone, we won't know each other. We don't know what is happening to whom. If we meet, we can get knowledge about others; from where we are coming. We can talk about each other. We can have 'sarsallah' [Nepali word for mutual advice, counselling, consultation; unlike other types of counselling it can occur between people with the same status].*

We were sitting on the ground in front of the school. As our conversation was taking a long time, I felt like I should have arranged a break for some refreshment. However, as there was no tea stall nearby this was not possible. There were some interruptions as well. On one occasion, the head teacher came over to us and spoke to me. It seemed as if he was unaware I was in conversation with a parent. We did not move from the place; instead I stopped the recording. When he moved away, we re-started our conversation.

Daya shared many experiences from her son's birth to the current time with me. Our conversation had already ended up taking nearly an hour when I had initially planned for 40 minutes.

At the end of this conversation Daya gave me the contact number of someone else in her neighbourhood who had a child with intellectual disability, whom she thought might be interested in participating in my study. I managed to meet up with this parent. I was grateful to Daya as she had openly shared everything she experienced in raising and educating her son; I thanked her and departed.

A week later Daya invited me to visit her home for a purely social visit. I saw that even though the home had only one room it was a generous-sized room, with three beds, the kitchen in one corner, some cupboards, and a store of goods and supplies in one corner. Daya offered me a cup of tea. I try to avoid tea, as I am not a tea lover. However, she insisted, and I felt I could not refuse because in Nepal it is considered rude not to accept such an offer when we are in someone's home as a guest. At that moment, I remembered an article I had read some time ago by a Canadian scholar, Sybille Manneschmidt (1995), in relation to conducting research in Nepal, called 'Ethnographic survival skills: Be ready to drink a lot of tea'. I was able to visit Daya and her family later during my follow-up field visit also. Further updated information about Daya is provided in Appendix J.

After the conversation, I felt like I had succeeded in my effort and gained enough bravery to conduct the subsequent interviews. Though I was a little nervous at the beginning, this being my first informal interview, by the end I was more at ease. I was satisfied I had successfully conducted my first interview for this study and, while I hoped I had I covered all the questions that I had in my mind, I was beginning to feel more confident about my future interviews.

4.3 Bel Bahadur

4.3.1 Background

I was introduced to Bel Bahadur by a worker from a non-government health organisation, who was working in the rural area where I had rented room for my field work. I personally met Bel Bahadur and talked about my area of interest, after which he agreed to talk to me. During this visit, he told me that he migrated with his family to their current location some eight years ago from his original home in the hills. This family runs a small grocery shop from their home. His elder son Padam, 30, who has a visual impairment, lives with them and is unmarried. Bel Bahadur's younger son was away working in Qatar. Since he was prepared to share his experiences of raising and caring for his son with me, we arranged to meet the following day for a longer conversation.

During my second visit, I talked to Bel Bahadur in more detail about his experience with Padam. We sat on chairs out the front of his home and grocery shop. It was around 5 pm in the evening and it would be dark very soon. Bel Bahadur was holding his grandson in his lap. There were many mosquitoes around us; I often had to chase them away. Padam was sitting on the floor in the passageway of their home. I could sense he was listening carefully to our conversation. Bel Bahadur's daughter-in-law also contributed to the conversation. Padam's mother came out from inside the house later but she sat quietly without speaking. We talked for about 40 minutes. Bel Bahadur told me that this was the first time that he was asked to share his experiences of caring for his son and I could see they were pleased to share their experiences with me.

I had first thought that, as Bel Bahadur was illiterate, his responses might be limited. However, after talking to him for a while, I realised that that was not the case. I was surprised at the level of detail he provided, and I began to see that this interview was more like a free-flowing conversation where I did not need to worry about probing or getting things in order. During this interview, I felt like Padam was also willing to tell me many things. However, I had not prepared questions for him, as it was intended to be a parent interview, so I arranged to return the following day for the third time, so that I could speak with Padam.

On the next day, it was a sunny but mild afternoon. Padam and I ended up talking for about 50 minutes sitting on the chairs in the back courtyard of their home. During the interview Padam's mother brought grapes and oranges to us. This time, she also contributed to the conversation. Later his father Bel Bahadur also came home from the field. Then we took photos and chatted for a while. This portrayal draws on all of my conversations with Bel Bahadur, Padam, Padam's mother and Padam's sister-in-law during my series of visits to their home. Once again, I present this portrayal in a series of sections reflecting the stages of this family's experiences of parenting and educating Padam.

4.3.2 Childhood

When asked to share the experiences of raising Padam from his birth, Bel Bahadur told me that when he was born, he was not at all like he is now, with a significant visual impairment. They had no idea he had a disability. He said that Padam used to wander quite a bit when he was small. His mother also shared that he was a bright boy. 'He would fetch grass for cattle; he was very strong; he would carry heavy loads. If he was climbing a tree, he could go to all tiny branches of the tree', said his mother. He used to go to *pandhero* (common watering place, well or stream), and would fetch water.

As time passed, however, he became disoriented when wandering and would fall down quite often, especially in the evening. Gradually Padam lost his vision. Initially, he could walk with the help of a torch of fire in the night but soon he could not see things at night. 'Then just by itself, it became darker and darker day by day', Padam said to me. To my question, 'What do you think is the cause of his disability?' Bel Bahadur replied:

> *I don't have any idea. None of our family members has ever had this kind of problem. No one was like this in our family history. According to a doctor, 'There should be some defects either in dad's eye or in mum's eye.' But both of us do not have any such defect. The doctor said, 'There is a small white spot, which is preventing him from seeing.' … I further said to the doctor, 'If it is possible, please replace his one eye with mine. I am ready to give my eye to him.' Then the doctor said, 'No, the replacement of eyes would not work either; this is due to the screen; if we take your eye, we need to put it into the screen, but his screen is damaged; and we cannot exchange the screen.' … Some people would also say that Kathmandu is also a place for his treatment, but I did not get any advice from the doctor. Without a doctor's advice, where can I take him? Thinking if it were due to some discontent of our ancestors' souls or an evil spirit, I took some steps towards that side. If 'jadibutis' [herbs and roots; traditional medicines] could help, I searched various jadibutis – I collected everything and whatever that was suggested to me by different people. … I left no stone unturned for his treatment, but nothing was successful.*

I appreciated that Bel Bahadur was explaining his responses in such detail. I decided to just let him talk as he wished and I probed only when he stopped.

When I asked Padam what he thought was the reason for his disability, he said:

> *A man came inside our home when we were living in the hill. He was a priest and did a 'Shraddha' [a ritual/ceremony in the Hindu religion performed each year in honour of dead family members including ancestors, in which family members offer their dead ancestors water, balls of rice pudding and so on] for us. From that day on, it started.*

As Padam was speaking, I noticed that unlike his father he gave answers in short sentences and sometimes just in a word. I also noticed that his throat would vibrate unusually while speaking. However, his voice was clear and he seemed quite confident while responding to my questions. In response to my probe 'What happened at that time? Could you please tell me more about it?' He replied, 'I fainted on that evening and then I stopped being able to see.'

His mother interrupted: 'I don't know; that's what he says. I have no idea.' His mother added, 'We regarded that man as our priest; but later it was found that he was married to a lower caste woman.' (She meant that one who marries a so-called lower caste woman becomes impure according to the Hindu caste system.) Padam added further: 'Then dad went to bring a witchdoctor. The witchdoctor did not come. He sent his brother, instead.'

After talking about Padam's childhood, his disability and treatment efforts, I went on to ask about his schooling experiences.

4.3.3 Schooling

Padam told me that he did his primary education at a school at his village while he was in the hills. He continued:

> *I wasn't able to sit the grade six exams. I had to leave the school. They expelled me. A teacher held my hand and led me home. He said, 'You cannot do anything in the school.' He told my dad, 'Look, brother-in-law!' (The teacher was our distant relative and would address my father as brother-in-law.) 'He is not able to see things; so, you do not send him to school. You will win by not sending him to the school.'*

Bel Bahadur told me that the teachers had informed him that, since his son could not recognise any letters any more, it would be best not to send him to the school. He added that, while he did not know about any schooling options available for people with visual impairment, he would pay any cost necessary for his son to be able to go to school.

When I was speaking to Bel Bahadur, I became aware of the myriad of experiences he had to share. Though I was very keen to listen to him, it was becoming darker, and the mosquitos around us were disturbing. For one moment, I thought of stopping the conversation for that day and continuing the conversation on the next day. However, I did not do that because I thought it might not be suitable for Bel Bahadur to spare time for me again. I also felt that he was enjoying the opportunity to share his experiences with me so we went beyond the usual amount of time and talked in the dark. I then asked about his experiences of other events that occurred in Padam's life.

4.3.4 Post-school options

I asked if Padam was able to do some household chores to support his family. Bel Bahadur replied, 'He does not do anything – absolutely nothing. He could just go to the toilet only. He knows the way to the toilet.' His daughter-in-law interrupted and said that sometimes he would wash his clothes. When his daughter-in-law interrupted him, I thought to myself that it seemed like this family was quite egalitarian given that such an interruption (a woman interrupting a man, and a daughter-in-law interrupting her father-in-law and even more so in a Brahmin or Chhetri families) is culturally not very common in Nepali society. She went on to tell me, 'He likes to eat rice, vegetables and pulses cooked at home but not the ready-made foods from the grocery store.'

Bel Bahadur then went on to share how he managed to get a disability card for Padam from a government office. He took him to the Women's Development Office. He requested them to provide a red card so that he could receive a good pension from the government. However, they just gave him a simple card – the green one, for which Padam gets 400 rupees (about 4 dollars) per month.

During these conversations, I became very aware that everyone in his family cared for and loved Padam very much. Padam was looking very strong, healthy and happy being at home, at the time of this interview. Padam told me, 'I wake up early in the morning with my father, do some prayers and then meditation.'

Bel Bahadur told me that, while he had not been able to access more schooling for his son, on one occasion, he sent Padam to a training course on making goods in the district headquarters. However, he did not complete it due to his need for assistance with toileting. He only attended for one or two days, though the course was planned to last for about one month. Bel Bahadur further told me that he was very worried about Padam's future.

> *If my son would have been married, he may have children, too. But who would agree to marry him – to a person with a disability and not educated? We might search for a girl with a disability, then who would take care of them? That is why it is very difficult for me. I do not know what to do next? ... Now, I have only God's grace. Everything is up to Him, whatever He wants He would do. I have this opinion. No one can do better than Him. I think, everything is as per His design. I am relying on Him. He gave the birth. He is obliged to look after.*

I felt like Bel Bahadur had such rich experiences. I asked, 'Buwa [father]! You have such rich experiences. Please tell me, what should be done to improve the future of people with disabilities like your son? Who should do what for this?' He replied:

> *I think government should help people with disabilities. Individuals cannot do much in this regard. If government does some arrangement for them, that would be very nice. Government is providing allowances to so many old age people, and to so many people with disabilities. … For him, too, they would have given a red card. If it were a red card, it would be easy for him to have food for his entire life.*

I felt glad that I was able to talk to Bel Bahadur, Padam and their family. I was reminded that people in rural areas tend to be very kind, welcoming and helpful. I expressed my gratitude to them for allowing me to come to their place and for sharing their experiences with me. Finally, we shared our contact information and I promised to visit them again and took my leave (I was able to meet Bel Bahadur and his family again during the follow-up field visit and updated information about Bel

Bahadur is provided in Appendix J). By this time, I was beginning to feel very confident with the relational approach to informal interviews and found myself looking forward to the next interview.

4.4 Anish

4.4.1 Background

It was 10:30 in the morning. Anish (from the *Tharu* ethnic group) had reached the school before me. I arrived half an hour later than the agreed time because I had missed my bus and had to take a rickshaw first and then a bus to reach the school from my accommodation. The school location was familiar to me as I had been to this school a couple of days before and had had a brief conversation with the head teacher, *aaya* and students with disabilities. When I reached the school, Anish was sitting on one of the beds in the children's hostel. There were three beds for the male students. Attached to this room were three other rooms – a bedroom for female students and the *aaya*, a kitchen, and a common room. This four-roomed hostel was in a separate school building and located inside the school premises. I greeted Anish and introduced myself. There were mosquito nets over the beds. I removed the net from one bed, so I could sit down. It was a cotton bed of about three- or four-inch thickness, placed on a wooden bed frame. With Anish's permission, I recorded the conversation, which lasted for 52 minutes.

Anish, a man with a visual impairment, had already contacted me on the phone a week before and chose to come to the school for the conversation. He has two siblings, including a younger brother who does not have a disability. His sister Susma also has a visual impairment, although it is more severe than his, and she had been studying in this school for five years and was in grade five at the time of this conversation. His sister was in the classroom at that time, so we met her after our conversation. During his introduction, Anish explained that his parents devoted 12 years to caring for him before having another child who was also born with a visual impairment. He told me that he had also attended this school from grade one to ten and that he started school later than his friends. Anish's family is from an officially declared disadvantaged group, *Tharu* ethnicity, an ancient tribe, most of whom live in the southern foothills of Nepal. Anish's mother tongue is *Tharu*, a different language than Nepali. I thought of requesting someone from the school staff to work as an interpreter between Anish and me, if Anish was not able to communicate well in Nepali. However, as we introduced each other, I found Anish was very fluent in Nepali. He told me that he was doing his intermediate degree from a local campus majoring in Nepali literature, as well as being involved in the journalism sector and had been working for a media company in the district. This portrayal is also presented in several sections reflecting the stages of experiences of Anish's family in caring for and educating Susma.

4.4.2 Early childhood

Our conversation started with Susma's early childhood. I asked Anish to tell me in detail about Susma from her birth; how their parents came to know about the problem; their initial response and their experiences in raising her; and her studies. Anish replied:

> *Both my sister and I were borne visually impaired. My family has done a lot for our treatment. We went to various places for our treatment. There is no place in Nepal we have not been. We have been to different places in India, too.*

He went on to tell me how his parents came to know for the first time that his sister also has a visual impairment and how they felt when they knew that their second child had the same type of disability as their first child.

> *Right after the birth of a child, people can tell if he/she is able to see or not. In two or three months' time, when others' babies are able to see and theirs could not, then parents know that the child is not going to see forever. The babies who have good eyes, they look different; and those who have bad eyes, it can be identified straight away. Therefore, we knew it when she was very small. We tried to arrange an eye operation at a very early stage, but unfortunately it has not been done until today. The nerve in one of her eyes has dried up and another eye moves continuously; that is why the operation is becoming impossible. For my parents, myself as their first child in the family had a visual disability; however, as I was a boy, they were less worried about me because sons stay at home. Then they got Susma, who is a girl or woman. In our society, girls have to go to another house when they get married. They were always worried about this; how this would be possible for her; how she would handle another home. It was a big challenge for our family. Later, when they found that the society is changing gradually – there is education in the society – then my parents felt a little relieved. Initially, there was huge suffering because of our disabilities. One may tolerate one case, but how can a family tolerate two such cases – two blind siblings – in one home? It was a huge wound to them.*

Anish also added another reason for his parents' distress. He explained that, while his eyes function at about 40%, Susma's eyes cannot distinguish anything except light and dark. She can tell if the light is on or not, or if there is sun or not. Her eyes have only that capacity, so her condition added further stress to them. In answer to my question as to what he thought was the cause of this problem, he explained:

> *If we believe in today's science and technology; it is hereditary or due to genes. However, so far as I know, we do not have any such person in our family clan, including in our distant past.*

> *I inquired about it in detail. So, in my view, during that time, in the late 1980s, pregnant women did not have a chance to take vitamins or medicines or to receive as much care as they would now. There might have been such facilities for urban women, but not for women like my mum, who was in a remote village. However, now, society has changed, and medicines are available everywhere. That was the time when there was no means of transportation, so there was difficulty in accessing medicines and facilities. Therefore, I think, it is due to the lack of proper vitamins and medicines.*

I was enjoying speaking with Anish and gaining insights from his detailed explanations. I also felt like he was pleased to share his experiences and opinions in detail. I wanted to know about his experiences in visiting doctors, so he recalled for me those moments when his sister and he visited doctors:

> *To the extent I remember, my sister and I had an appointment for our eye operations at Tilganga [the biggest eye hospital in Nepal]. It was on 28 May 2010. The doctor said, 'It is a cataract, it is congenital. It is because your mother did not receive proper care when she was pregnant; she did not take iron pills and vitamins.' After some time, they took my sister and me to the operating theatre. They did not do her operation, but they did mine.*

In addition to the medical treatment, I asked if they were taken to witchdoctors and shamans. To respond to this question, Anish thought for a moment and then continued. He said that visiting witchdoctors and shamans is a common practice in their community and both of these siblings were taken to them. Unlike the answers to other questions for which Anish had long explanations and examples, this time he did not explain in detail about witchdoctors and shamanistic treatment. He just told me that their parents tried many options but did not succeed.

4.4.3 Schooling

I asked Anish to tell me about their experiences of schooling, particularly the schooling of his sister Susma; when did his family think about her schooling and education; what made them think about schooling and so on? Anish recalled that when he was studying in this school, there were only two students older than him. Both of them were 'sisters' (girls), and at the time of this interview they were perhaps doing their master's degrees. He stated:

> *My parents saw those two sisters who were studying with me in this school. If we talk about the local example, in the village next to ours, there are two girls with visual impairment, who are teachers in local schools. That made my parents aware about the role education can play. They realised that girls can also study and do something, if they get education. I also told my parents that education makes girls and people with disability able to do something. I*

> *convinced them; I told success stories. I gave examples of Jhamak Kumari Ghimire and Parijat.*[19] *My parents were then able to get some knowledge from those examples and stories. In this way, I brought my sister here for admission.*

He added that during that time his parents saw and listened to many things about girls' education, and about educational provision for children with disabilities, through local TV and radio. Anish would explain with examples for most of his responses. Then I wanted to know about their experiences when they brought Susma to the school for the first time. In response, he said:

> *On that day, we three people – my father, my sister and I – came to the school. The resource teacher knew that my sister was also not able to see. He said that 'It's OK. She will first learn Nepali and English alphabets. When she goes home during the break, you also help her learn.' In this way, he encouraged us.*

I went on to probe how Susma was doing in the school now; Anish responded that he and his parents felt satisfied with Susma's progress as she had done well:

> *I think she has progressed tremendously after she came to this school, for example she has progressed in speaking. She knows how to express views in different situations; whom to respect and how to show respect towards them; how to behave towards them; and how to behave to juniors. She knows that she has to study for a good future. … When there is a school break, she would ring us and tell us that she wanted to come home. When school is starting after the break, she says, 'I have to go to school. It is time to go.' She does not want to miss the classes.*

He then added that his family and relatives also felt good about both of these siblings, though they were very stressed previously. They were worried about how Anish and Susma would manage their livelihood. When Anish brought his sister to the same school, they started to think 'Susma is now studying, and her brother also did quite well. He has reached that level of success. Her brother is doing well and sings well. In future, she can also be a well-known singer.' Anish told me about his dream for his sister:

> *I do not have big ambitions for myself; but I want her to become a singer. I have an aim to make her a singer at any cost. I have that determination.*

To realise his dream for his sister, he thought that the school should be more supportive:

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[19] Jhamak Kumari Ghimire is an iconic figure in the disability sector in Nepal. She is a renowned poet and writer and has won several medals. She has multiple disabilities. She uses her feet to write. Parijat was another renowned female writer, who had severe polio, and was an activist.

> *In the school, in addition to the regular studies, there should be music classes. There should be instruments like harmonium, guitar, madal [a typical Nepali music instrument]. I have seen those goods in other schools. Study [academic studies based on books] is also important. Therefore, it's not my intention that she should not focus on the bookish knowledge; I don't mean that she should be singing all the time. You know, I am not saying that. All should focus on their study during study time. However, in the leisure time, instead of using the mind for other useless things, if we focus on and practise music, that would be good. Therefore, it would be productive if the school manages to have a musician with instruments. Unfortunately, there is nothing in this school. However, what I can do for this is – I won't say that I will be able to come daily – but, I can come once a week and teach them music. That's what I think.*

When I asked if he had made any recordings of his songs, he said that he, with his sister, had recently released one album. When I asked Anish if he could sing a line for me, he sang a stanza of one of his songs.

> *This song is in my language. By the end of May this year, we have a plan to make it in Nepali. Ok, let me present it in my language first.*
>
> > *Bechain bahi mann tohar pyar mein, Hardam harpal tohar yaad mein.*
>
> *The Nepali meaning of this stanza is: bechain chha yo mann timro mayamaa; sadhai bhari timro samjhanamaa. [This heart is restless in your love; the heart is hectic every moment in recollecting the past memories; my translation.]*
>
> *We were able to release it after a big struggle. Money comes first for everything. We invested almost 19 to 20 thousand rupees for this (about $200). We have uploaded it on YouTube also, but we have not yet produced a video.*

I then asked about the family's involvement in school activities; how often parents would visit the school or how often head teachers or teachers would invite parents to the school. He mentioned that he would come to drop and collect Susma before and after the school holidays. Then when he or his parents wanted to see her, they would just call her. If they wanted to see her face to face, then they would come to the school for a short visit. Moreover, if Anish happens to pass by this area while going somewhere for other work, he also drops in to see his sister. He also shared that sometimes his parents also come for a parent assembly. When I probed more on what they do during a parent assembly, Anish said that he had come just once. He added:

> *We would just listen to the teachers discussing who is going to be the chair and deputy chair in the committee, and so on. When someone wishes to run for the chair, he/she would request our votes. Mainly those types of things are done in the parent assembly.*

To my question about whether they were asked for any suggestions to enhance students' progress and learning during those assemblies, he said:

> *I haven't been asked about other things such as what the students want to do in the school or what they don't want to do. For example, if we talk about the music in the school, students want to have musical instruments. They definitely want to listen to music. If the school asks parents about these things, that would be good. They haven't asked me about it. I don't know if they asked any of us separately.*

In addition, when I asked Anish if he saw any need for regular interaction between parents and school professionals, he explained that this type of interaction would be helpful because both parents and teachers would have the opportunity to express the difficulties they have faced. Parents will be able to know about how their children are doing at the school. Moreover, to Anish, children can share with their family what they cannot share with the teacher. He continued:

> *Students may ask family members to tell those things to their teachers on their behalf – 'This is happening this way; this is managed this way; this is not good; this has to be done this way; please do this for us.' That's what students might have in their mind and want to tell the school through the family members. For this, we can ask the school to organise this type of interaction, but I think, it is the school who should take the initiative. I think, there is a lot of benefits from this. There are a lot of things that the students cannot tell the teachers. We, parents, can convey those things to the teachers during these interactions. When the teachers learn about it, they will definitely do something. Then, also, if teachers have any comments – positive or negative – about our sisters, or anything that needs improvement by us, they can tell us in those interactions. Then we can improve.*

When Anish was giving such detailed explanations about the importance of parents' and teachers' interactions, I felt like I was learning a lot from his account about parents' experiences. It was really an encouraging conversation in that he answered each of my questions with detailed explanations. I had not thought that he would have such broad experiences before starting the conversation. In the meantime, I decided to ask a more abstract question in order to further draw out his thinking.

I asked him if he had any advice about how school professionals can connect to parents or how they should handle parents' concerns. I asked him to imagine he was a head teacher or a teacher and tell me what he would do to engage parents if he was in that role. He stated:

> *For that, they should invite all parents in one place. Then they should tell us the matters or issues in detail, such as, 'We are operating the hostel for children with visual impairment; the government is not able to provide everything we need to run the hostel. We will need this and this thing to effectively run the school and hostel.' In this way, they can persuade the parents. 'If you know any organisations working in this area, please connect them to us. We would be able to do more for the benefit of the children.' In this way, they can put things in front of parents. Sometimes what can happen is, as soon as school people fulfil their interests, then they do not care about the parents. But this is not good. People should not do that. Parents should be contacted regularly for their advice and suggestions. Even when they are able to manage things well and properly, parents must be consulted. In that case, they may tell parents, 'We have managed the things in this way; please advise us what we need to do further.'*

He added that parents should also come forward to support the school:

> *Government provides only the hostel, meals and books. Then we need various other things such as cupboards. The school may not able to manage everything, since the school cannot afford the cost. There might be some other organisations that can support this. Teachers can inquire about that by themselves, but parents should also think, 'It's a school for our children; what should I do for this?' Parents must have concerns in such cases.*

By this time our conversation was coming to an end. Anish gave me his contact number and asked me to contact him anytime if I needed any further information. I thanked him for participating in the conversation and sharing his feelings and experiences about caring for and schooling his sister. He told me about his involvement with a local institution that advocates on behalf of people with disabilities. He invited me to visit his organisation any time during my field work. I told him that I would try to visit him again. Then, we departed. However, unfortunately, I could not visit his organisation during my stay in the field due to my busy schedule, which I later regretted.

4.5 Sheetal

4.5.1 Background

When a resident from the area where I rented a room for my field study heard about my research, he told me about Sheetal – the mother of a 12-year-old boy with severe cerebral palsy. I asked him to give Sheetal my contact details in case she wanted to speak to me about her experiences bringing up her son. After a while, I received a call from Sheetal to let me know she was prepared to speak with me. I went to her rented room for the conversation in the afternoon. The weather was a little hot outside but inside the room it was quite mild. Sheetal, 38, lived there with her two sons aged 12 and 17. Her husband had died four years ago. Her room was about three metres by four metres, and housed two beds, a kitchen rack and a cupboard, and all the belongings of her family of three. In one of the corners was a portable gas cylinder and a stove. After a brief introduction, we started our conversation, which once again I have structured in unfolding sequences of early childhood and schooling experiences.

4.5.2 Early childhood

Finding myself very familiar with my questions by now, I began in my usual way ‘Could you please tell me about your son from birth?’ In response, Sheetal told me:

> *Buddhi was born in Pokhara. It was about midnight. He was my second son. I bathed and breastfed him. In the morning, he began to vomit so we took him to the hospital. The doctors said that he might have absorbed something from the fluids in the womb.*

In response to my probe, ‘So, vomiting was the first symptom?’, she replied, speaking very fast, almost without stopping:

> *Yes, it was. He vomited; it was like fizz from soap. After they gave him an endoscopy in the hospital, he did not vomit, so we came back home the next day. When I was breastfeeding him, he started to vomit again, and we thought that he should not be kept at home, so we went to the hospital. We stayed in the hospital for nine days. However, he did not stop vomiting; he was diagnosed with jaundice. I gave him a warm massage. Then the doctors advised us to take him to Kathmandu. The doctors forewarned us that an x-ray could fuse the respiratory canal and food canal and cause the blockage of respiration. However, later, this did not happen. In the meantime, we came home just for one day for nwaran [a name-giving ritual which happens on the ninth day after a baby’s birth]. We stayed in the hospital in Kathmandu for 15 days, with him on the fifth floor and us on the ground floor. No progress was seen though. They did an x-ray and other examinations, but nothing was found. So, we brought him back home. He would vomit after every feeding, until he was eight months old. He would stiffen his body to vomit. …*
>
> *I have been to the hospital countless times. There hasn’t been any moment of joy in my life since his birth. Nevertheless, had his father been with us, I would share my sorrows. It wasn’t in our fortune to live together. I have a lot of pain, you can imagine. (She cries) What to do? Everything has to be tolerated in life. Everything has to be in accordance with our fate. Now, after his father’s death, I have admitted him to hospital three times. … He was given various medicines and after four or five months, he became a little better. Then the doctors drew fluid from his spinal cord four times as they thought he may have meningitis, which made him so weak. Although doctors might have done this [drawn fluid from the spinal cord] for a good*

> *reason, it turned out to be damaging for him. It was the doctors' great mistake. Now, we can understand these things, but at that time, we were not much aware about all this. … He couldn't walk, couldn't speak, and couldn't do anything. We all love our children. I tried everything people or well-wishers suggested. One of my brothers in Pokhara suggested I pluck seven shoots of dubo [a small herb] early in the morning, grind them and feed him one spoonful per day for 20 to 22 days. 'That helps some children speak', he said. I believed that suggestion, as nothing was working previously. I thought that could help him. However, due to that, he fainted. We admitted him to hospital. He fainted up to six times a day by the time he was four. … The doctors did a CT scan and the brain nerve was found to be relatively thin. So, they gave him medicines related to the nerves – sodium vampirine and neuro cetaprime [she showed me the medications]. After this he began to hear. He now understands things well. He greets guests; looks at their handbag to see if they have brought something for him. However, the vomiting problem is still there. Had he had not got this problem, or had he been able to digest what he eats, he would have been able to walk by now.*

Sheetal was telling me her stories in detail and I did not want to stop her, as she had so much to share, although I had also a lot of questions to ask her. She cried from time to time. In a gap in our conversation I asked her if her son was able to walk now. She told me he could only walk by holding on to a wall, and with support he could climb upstairs. She said:

> *When I go to work, I lock him up in the room. My son knows the office time. He would tell me to go to the office; waves his hands to do a 'bye-bye'. He has some toys in the room. He sleeps and wakes up but does not cry. He however cannot go to the toilet.*

She showed me a toilet pot, which was kept under the bed frame, in front of me. She then went on to tell me that she would reach her office by 8 am, come home at 11 am for one hour to feed her son and then go back to office and would stay there until 6. She said her jobs at the office included cleaning and serving water and tea to the staff. She continued:

> *He likes moving things. He moves this fan [she indicates the ceiling fan] with a broom. There is always a danger of electric shocks. We would detach the electric cable from the fan. Look, he is watching the fan now. He has broken several fans. He would turn the switch on and off repeatedly. … Last year, a packet of blood was transfused to him; this has made him more active. … Now, he is doing OK. He eats well. He eats lentils, rice, vegetables, saatu [flour made of roasted corn or barley], puffed rice, dried spicy pulses, and noodle soup. He eats egg and meat, too. … I have to be careful while feeding him. Only just a bit at a time, as he cannot digest if I feed him more. … He survived because of salines. How he became like this, is truly a surprise.*

She added:

> *The doctor suggested we take him to Delhi at any cost. But I could not afford it. … I didn't get a chance to get higher degrees. If I had a higher degree, it would have been a different situation. At that time, people were hesitant about girls' education. I was married when I was 17. I hadn't had even an SLC [School Leaving Certificate – grade 10]. I was the first daughter-in-law at home, I didn't have the privilege to go to school after my marriage. Now I feel sad about it.*

I asked her if anyone in her family advised her to find about any other domestic or traditional rural medicines, *jadibutis* (roots and herbs) or to see witchdoctors. In response, she told me:

> *I went to see the witchdoctors. They said, 'This is all because of the grahadasha' [good and bad aspects of the planets determined by their positions at the time of birth, which accords with one's horoscope]. … I also visited many temples. But that didn't work. Most of the time, I took him to the hospitals. … My inner heart thinks if one method is not working, why not try another; maybe that could work. But the ultimate result is what is designed by the Supreme. Our design cannot work in any case; it happens as per His wish.*

She became silent for a moment. I was listening quietly as she was telling me everything in detail about the hospital visits, follow-up issues, medications and her son's current situation. During our time together, she would sometimes talk to her son. On one occasion, she said to him 'Honey! You have a cap; give it to uncle [me]; he will wear it.' She then told me, 'He can plug in mobiles, charge lights, can open and shut down the laptop. He has a good brain. But he is not able to speak.' By this time, we had talked a lot about his illness, his treatments and their financial situation. Now, I felt I should ask about her experiences regarding Buddhi's education.

4.5.3 (Non-) schooling

To my question about whether she had inquired about any schooling options for her son, Sheetal replied:

> *I went to Deepnagar to inquire about his school. I carried him on my back. They had day classes. I was prepared to keep him in that class, so that he could learn something and become active. … In the school, they said, 'The child should walk and take care of himself, such as he should be able to go to the toilet by himself to be enrolled here.' They told me that they could enrol only those children who need only a minimum level of care. They did not enrol him.*

In response to my inquiry whether she went there just once; she replied, ‘Yes, just one time. Why would I go so frequently when they say this? Shouldn’t I go to work to earn a living?’ She continued:

> *When they have this view about my child, how can I afford to go to different places and inquire about the same thing? I also thought, it’s the same everywhere.*

There were a number of interruptions during our conversation, such as when Buddhi wanted to relieve himself, so he signalled for a pot; Sheetal pulled out a pot, which was kept under the bed right in front of me. She helped him to use the pot and put it back under the bed. Buddhi then wanted me to put some things on top of the cupboard and to hang a bag on a nail on the wall. I helped him do that. Sheetal asked him to sit quietly.

Then I asked her, ‘Do you think that the school should teach Buddhi to walk and to go to the toilet and these kinds of skills?’ She replied:

> *If he could get that chance, I think he can learn those things. He has a good brain to learn things. … I was not able to go to other places. There is no one to help me; no one to advise me. If there were someone who could tell me the place to go or do something, I would have done that.*

Then I asked, ‘If a school keeps him in a hostel with all facilities, would you be able to keep him in the hostel there?’ In response, she said:

> *I think I would not be able to keep him in the hostel if it is very far from here. The colleagues in my office also advised me that I should send him to a school in Pokhara for his bright future and I should compromise. … He doesn’t eat with others; he would rather cry and go to sleep hungry. What can we do in such a case? It’s a mother’s heart, I cannot leave him in the school in this situation.*

She added:

> *I need to carry him on my back to the market. How do I lift him, you can imagine? If we ride a rickshaw, they charge full fare even for him. Once, I was coming from Arghakhanchi in a bus. I kept him on my lap in order to vacate a seat for another passenger. But they charged full fare for him as well, though he is also entitled to discounts. … Everyone is selfish now in this age. No one understands another’s difficulties. Rich people favour the rich. The poor are not looked after by anyone. No one would consider our pain. … If both sons were normal, it would be easy to tolerate my husband’s death; because everyone has to die. Some die quite young; others live their full age. If my husband was alive, I would not have to worry about the finances, and I would only be responsible for taking care of the children. (She cries.)*

Then after a while, she said, ‘I think we must struggle with this. We should not accept defeat; we should seek ways to proceed.’ At this time, I felt she had enough courage and she did not want to give up. I also noticed that she mentioned fate, fortune and the death of her husband many times during the conversation. By this time, I felt like she was linking various events while answering my queries. She happily shared her stories with me in detail, as if this helped to relieve some of her burden of raising her son. When I asked what dreams she had for Buddhi, she said:

> *I don’t have big dreams for Buddhi … If he could walk and eat by himself and go to the toilet, then that would be good for me. … I didn’t expect him to study a lot and become a thulo manchhe [a big person]. If he could walk, he should know where he is heading. Otherwise, he wouldn’t be able to figure out the places and streets. If he just walks from home and doesn’t know anything, then that will be another trouble for me.*

I also asked her if she had sought any support from other agencies such as village councils. She recalled:

> *I did talk to the doctor at the Zonal Hospital for medical support. Then the doctor recommended free medicine. I got a strip of medicine that lasted for only 20 days. I could not get access to such medicines again. I don’t know much about other support. Had there been anyone to show me the way, certainly, I would have done accordingly. … Village councils should provide support to people with disabilities. They should provide us whatever they receive from the centre [Kathmandu]. For my child, if they support me to buy medicine, that would be better. It costs about 2000 rupees [about $20] per month.*

By this time, we had been talking for more than one hour. She told me that she was not in a rush that day as ‘Today is Saturday, so I have time; otherwise I would have to go to the office. I would be busy the whole day.’ She prepared lemon tea for me and gave me some biscuits. The room was a bit smelly (from the toilet pot) and I did not really want to have the snacks. However, I felt it would be rude to refuse the offer.

I asked if she wanted to add anything and, in reply, she said:

> *What I think I am telling you is all my bitter experiences and sufferings; but I wouldn’t tell it to everyone out there. What’s the use of doing that? I have my sufferings within myself; I am struggling with it. … People are different with different attitudes. That’s why I don’t tell everything to others.*

By this time, our conversation was coming to a close and it was time for me to go. I was so touched by Sheetal’s story that I felt that my role should not be limited to being an interviewer. I felt that it would not be ethical for me if I did not do what I could to help her. I was not just listening during the interview; the conversation was bringing up my sense of duty, morality, social justice and activism. I felt that I had to do something to help Sheetal. Though it was not quite within the scope of my visit to her, I suggested she meet one of the doctors known to me for free medication. I gave her my contact information and thanked her. She also gave me her telephone number and asked me to contact her if I needed any more information in the future. Then I departed.

What stayed with me after the interview was Sheetal's limited finances and her inability to enrol her son in a school. When she was talking about the school not admitting her son, I felt I should talk to a school head teacher or the admitting authority so that something could be done to help her. I later found the contact address of a head teacher of a nearby special school and rang them. I asked if they could enrol a boy like Sheetal's son. I tactfully suggested that it could really be a *punya karma* (a Sanskrit word for saintly, sacred, just or righteous action that could lead people to salvation). The head teacher promised to try her best to take him, so I then rang Sheetal and asked her to meet with the head teacher.

4.6 Chapter summary

In this chapter, I have presented portrayals of four parents from the western rural area of Nepal who live with their children with disabilities, focusing on their experiences of caring for their children and their attempts to connect with schools. These portrayals reflect the diverse ethnic and caste backgrounds and experiences of the participants in this research. They were presented in such a way as to give a picture of the context and background in which the conversations with them took place. I also included some of the feelings and thoughts that arose within me during these informal interview conversations. Each of the parents expressed their experiences in detail. The portrayals have revealed the challenges, sorrows, choices, dreams and opportunities of parents. Each individual's situation is somewhat unique, but there are also commonalities and therefore they may enable us to better understand parenting experiences and practices in the rural context of Nepal. These portrayals provide evidence that parents take great care of their children with disabilities, want to find the causes of their disabilities, make sacrifices, demonstrate a willingness and capacity for involvement in their schooling, and at the same time also feel frustrated about limited access to services and information about proper medical care, and are concerned about transport and distance issues. In the following chapter, I revisit these portrayals along with data gathered from other parent participants and professionals to further illuminate these findings in thematic form.

CHAPTER 5 - THEMATIC FINDINGS: REVEALING PARENTS' JOURNEYS OF RAISING THEIR CHILDREN WITH DISABILITIES AND ATTEMPTS TO CONNECT WITH THEIR CHILDREN'S SCHOOLING

> **Knowing Fish**: One day Chuang Tzu and a friend were walking by a river. 'Look at the fish swimming about', said Chuang Tzu. 'They are really enjoying themselves.' 'You are not a fish', replied the friend. 'So, you can't truly know that they are enjoying themselves.' 'You are not me', said Chuang Tzu. 'So how do you know that I do not know that the fish are enjoying themselves?' (A Taoist story).[20]

5.1 Chapter introduction

In this chapter I present a series of narratives created from a thematic analysis of all the data from interviews and focus group discussions including the portrayals presented in the previous chapter. This chapter comprises two main sections. Section 5.2 presents exemplifying quotations extracted from the four detailed portrayals discussed in Chapter 4 and from the remaining 15 transcripts of parents' interviews and four transcripts of focus group discussions with professionals comprising teachers, head teachers, community members and government officials. The themes that were identified from the data thus are organised in two stages as a way of revealing parents' journeys of raising their children with disabilities and connecting with their schooling.

In Section 5.3, I expand and revisit the themes that emerged in the previous section and present these in a series of narratives with a view to exploring their underlying meanings. These narratives are presented in chronological order, showing how the journeys of the parents in this research are revealed through the various barriers, challenges, opportunities and joys they experienced while parenting their children with disabilities and seeking to connect with their schooling. Finally, in this chapter I also provide an *in-situ* reflection on conducting the research proper and presenting research data before I readied myself for interpretation of the findings in the next chapter.

5.2 Identifying themes

To arrive at the final set of themes, prior to presenting them here, I visited and revisited all sources of data. Firstly, I developed themes based on my deeper engagement with the four portrayals offered in the previous chapter; I came up with 15 themes at this stage. Secondly, I closely read and reread all transcripts of the remaining interviews and focus groups to uncover patterns to either reinforce the themes obtained from the four portrayals or to identify any new or additional themes;

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[20] A Taoist story from *Zen stories to tell your neighbours* (p. 45) (Retrieved on 25 March 2019 from http://www.arvindguptatoys.com/arvindgupta/zen-for-neighbours.pdf).

through this process, four additional themes were identified.[21] During this process, I grouped and regrouped, and wrote and rewrote those themes several times to find the appropriate headings for the themes so that they would reflect the message the participants were conveying. In doing so, I also shared the themes with my peers, critical friends and with my supervisors, seeking out their feedback. Their advice was instrumental in improving/finding the headings for each theme, which are worded with a view to carrying a narrative flavour.

The themes identified relate to the two distinct stages of the parental journey. The first stage covers parents' experiences in dealing with the disability at home, in the community and in healthcare centres, understanding the disabilities of their newborn and searching for a cure, if any. The second stage focuses on the experiences and insights of participants about schooling these children. While the first stage relates to the parental journey of raising the children and seeking remedies, the second stage includes the journeys of the parents of this research revealing how they realised (or did not realise) a need for schooling options for their children with disabilities.

I have characterised the first stage of the parental journey as: 'The stage of uncertainty: Birth, belief and search for a cure'. The views and experiences expressed by the parents in this research included their struggles and successes in parenting their children with disabilities, as well as their hopes for the future. Therefore, this stage relates to their concerns about their children's birth, care and health and includes their challenges, and experiences of sorrow and despair upon diagnosis and while seeking a cure. In addition, the cultural aspect of gender in relation to the dual challenge of disability for girls and mothers as caretakers of children with disabilities is considered. This overall stage is structured into nine themes. The themes identified for this stage are:

- a stressful start: the birth of a child with a disability;
- seeking answers;
- search for a cure;
- getting a diagnosis;
- 'We can't afford that';
- reality check;
- a pleasant surprise;
- 'Feeling proud of our child';
- the cultural face of gender.

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[21] The four additional themes identified at this stage were: a lack of welcome for children, 'They're different from us', poor quality services and 'No parent friendly environment and support for us'.

The next stage is characterised as ‘The stage of disappointment: Hope, schooling and untapped potential’ and is once again structured into several headings. This stage included parents’ experiences while attempting to connect with the schooling of their children with disabilities, for example, exploring schooling options for their children, their hopes for their children from the schooling, feelings of pride in their children’s achievement, and so on. Since by this stage the parents have connected with schools, most of these themes include quotations from the focus group participants (teachers, head teachers, community members and local government officials). The themes identified for this stage are:

- ‘Nothing is more important than education!’;
- inspiring role models;
- ‘I can see a huge difference’: the benefits of schooling;
- a lack of welcome for children;
- ‘They’re different from us’;
- poor quality services;
- parents’ expectations of schooling;
- ‘No parent-friendly environment and support for us’;
- lack of two-way communication; and
- parents keen to be involved in schools.

These themes are reflected in the following table. In the first column, selected quotations from participants are clustered to exemplify the themes identified in the second column. This provides evidence that the participants’ voices are integrated and grounded in the themes generated in this relational research. In this section, participants’ pseudonyms are used to refer to the quotations (please refer to Table 3.1 and Table 3.3). Moreover, the themes taken from participants’ verbatim quotations are placed in quotation marks, in the second column.

Table 5.1: Exemplifying quotations and identified themes

Exemplifying quotations	Identified themes
Stage One: The stage of uncertainty: Birth, belief and search for a cure	
She was our first child. I cannot express how much suffering we had when we knew that she has lost her eyesight. (Karuna, mother of a girl with a visual impairment) *We thought that everything would be OK after some time. But when she turned three, we knew that she was not quite normal. (Kushal, mother of a girl with intellectual impairment)*	**A stressful start: the birth of a child with a disability**

Exemplifying quotations	Identified themes
It was so sad to hear that treatment was not possible even through surgery. (Shivani, grandmother of a girl with intellectual disability) *He is unable to control his organs due to the wound in his brain and there is no way to cure it. (Pawan, father of a boy with intellectual disability)* *In the village, the people would say, 'Hey "kana" [blind boy]. Hey "kana ki budi ama" [grandma of a blind]!' Is it us who made him blind? It is so depressing to hear that word [blind] from other people. (Tiru, grandmother of a boy with visual impairment)*	
I think, everything is as per His [god's] design. I am relying on Him. He gave the birth. He is obliged to look after. (Bel Bahadur) *Some ignorant people would say, 'Their parents must have done some sins, so they got these children with disabilities.' But this is not true. I believe in doctors. It is Down syndrome. (Kushal)* *The god creates some people OK, and others with a disability. (Miya, brother-in-law of a boy with hearing impairment)* *The doctors said that he might have absorbed something from the fluids in the womb. (Sheetal, mother of a boy with multiple disabilities)* *I think it was due to that water [fluid], which was accumulated in her head [brain] – that made her scratch her eyes, which then made her blind. (Karuna)*	**Seeking answers**
We went to Siddha Baba temple and freed a couple of pigeons to fulfil our vows and please the god, so that she would become OK. (Shivani) *No temple is left; we took him to everywhere – Balaji Rajasthan, India; Sheela in Syangja; and many other places. (Hari, grandfather of a child with intellectual disability)* *If it is due to her fate, maybe whatever efforts we would make, we may not have avoided the result. If it was her fortune, it occurs by any means. (Karuna)* *Thinking that if it was due to some dissatisfaction of my ancestors' souls or due to an evil spirit; I also took some steps towards that side. … I searched various Jadibutis – I collected everything and did whatever was suggested by different people. (Bel Bahadur)* *There was a witchdoctor named Tamang. We also took my son to him. (Pawan, father of a boy with intellectual disability)*	**Search for a cure**
They [doctors] call them magajian [related to brain] or susta [slow]. This means a 20-year-old person with this disability has a mind equivalent to 2 years old. (Hari). *According to a doctor, 'it is because of his eye screen, and it is due to some genetic defects that there should be some defects either in dad's eye or in mum's eye.' (Bel Bahadur)* *They said that my daughter falls under a category named 'Down syndrome'. Children with Down syndrome have short fingers, hands and legs and also have a slow brain. (Kushal)*	**Getting a diagnosis**

Exemplifying quotations	Identified themes
Even the doctors don't know that. The doctor would only say that their brain does not function fully. (Hari)	
I did not have even five rupees [5 cents] with me at that time. (Tiru) *We are poor people; we are not able to take her to different places. (Karuna)* *I do not have the money; I cannot take him to Kathmandu. …We just have a small farm only. Going different places for treatment is expensive and we can't afford that. (Prakash)*	**'We can't afford that'**
The doctor said, 'She had this problem from birth, it is not a disease. Better, you keep her at home. Medicine is not going to work for her. We cannot do much in this case.' (Choudhary, father of a girl with visual impairment) *We were hoping that she would be able to see more after taking her to there [a hospital in India], but nothing improved. (Karuna)* *The doctor said that he did not have any problem in the outer ear, but he had problems in his inner ears. (Daya)* *We took him to Kanpur, Lucknow, and other cities in India. Doctors suggested nothing. We are not taking him to any hospital anymore. (Miya)* *He [the child specialist] said that my son's development is not possible through the medicines, not in any hospital. (Biswa, father of a boy with intellectual disability)*	**Reality check**
He could not move but would just crawl, using his chest. … We did many things for him. Then he started to walk. He is talented now. We were not expecting him to become like this. (Daya) *He was critical, he was given oxygen. But, later, on the same day, his condition improved largely. I didn't have any hope about him. I was thinking that he would be dying soon. He didn't have any life at one point. From where he got life? (Tulia, mother of a boy with intellectual disability)* *We left the hospital and waited as it was expected he would die soon, and we would bury him and go home. After two hours, he started to suck the glucose drops. ... We were not hopeful that he would become what he is today. (Biswa)*	**A pleasant surprise**
One morning, Dipesh drove the tractor. He ploughed the land, moving it over the muddy farm field. We all – father, mother, brother – watched it and felt happy in our heart. He is very smart. (Prakash) *He greets his father's sister or grandma by touching their feet. He has very good manners. (Tiru)* *She makes us cry by singing those types of songs [songs about people with disabilities]. (Karuna)* *She watches carefully for vehicles before crossing the road. She knows that and is very careful about it. (Kushal)* *He would unleash the buffaloes, take them to the jungle, bring them back and leash them again. Then he would clean up the buffalo dung. He knows which program is*	**'Feeling proud of our child'**

Exemplifying quotations	Identified themes
coming at what time on TV and searches channels quicker than we search. We feel proud of our child. (Biswa)	
We haven't left her alone; because today's atmosphere is not good and safe. She is a girl, which makes us always stressed and cautious. (Kushal) *I am not able to register the birth of my daughter. Her father left us. (Sarita)* *I took her to hospital again – twice, on the same day. … He [her husband] would never go to the hospital; I would just go there alone. (Karuna)* *I need to feed him; I need to help him relieve himself. He does everything on beds. I wash clothes and do the dishes, cleaning and mopping. … I need to prepare lunch for his father and the other children. (Tulia)* *I visited the local hospital six times. I asked Saput's father to take him to Kathmandu. But he did not listen to me. (Tiru)*	**The cultural face of gender**
Stage Two: The stage of disappointment: Hope, schooling and untapped potential	
I was telling my family members that 'we should send her to school; we should not keep her at home, for she cannot see'. Nothing is more important than education. (Karuna) *For his good future, we are ready to leave him in the hostel even in Kathmandu. (Haree, grandmother of a boy with intellectual disability, family interview)* *What will happen tomorrow, if we keep him with us at home? If you love them very much and keep them at home, you spoil their future. (Prakash)* *Who would feed these children, who have visual disability, in future? If they get education, they can do something. (Narayan)* *I found parents worrying about education for their children with disabilities. They think, 'I should provide an environment so that my child would be able to learn and become something.' (Dambar, teacher, focus group participant]*	**'Nothing is more important than education!'**
Look, Dhundi sir, who has visual impairment like my daughter, struggled a lot. Now he has become a teacher. (Karuna) *When I saw the [visually impaired] teacher here. He has become a teacher. Why would my child not be able to become a teacher? (Tiru)* *My parents saw those two sisters who were studying with me in this school and who later became teachers. That made my parents realise that girls with disability can also study and do something, if they get education. (Anish)* *Parents would say, 'if he/she is able to read and write, why not my child? I will also send my child to the school.' (Dambar, focus group participant)*	**Inspiring role models**
She [now] behaves completely differently. There are two or three children at our home, but they don't write as nice as her. It is very good, sir. (Choudhary) *Playing, stealing, fighting; that's what he would do at home before coming here [the school]. Now it is far better. (Prakash)*	**'I can see a huge difference': the benefits of schooling**

Exemplifying quotations	Identified themes
He has become smart and talented by being in the school. He can find the way to the school by himself. I can see a huge difference, like the difference between earth and sky, in him before coming to this school and what he is now. (Miya) *Students are able to learn to play together; respect each other; entertain each other; and acknowledge differences. The children with disability benefit the most. Schools provide them that opportunity. (Dambar)* *We can see the changes now. When their peers are not able to see, the normal children would hold them and lead them to the right places. (Rakesh, focus group participant)*	
Teachers would just say, 'other kids are complaining about your son that he has done this, and he has done that; it would be good if you do not send him to the school. (Prakash) *I haven't gone anywhere to inquire about school, as no one came to me and suggested school for him. (Tulia)* *'We are not able to teach your child. This is not a school for your child.' That's how parents are treated by the school in the beginning. (Dambar, teacher, focus group participant)* *There is difficulty at the schools' side also. Parents should understand this. (Laxu, teacher, focus group participant)*	**A lack of welcome for children**
For most schools in the country, everybody thinks that a special class is not part of their school. It is different. It is for children with disabilities. They are different from us. It is separate because there is a separate class, a separate teacher, and separate training and so on. (Dambar, focus group participant) *We think that it is their [resource teachers'] sole responsibility to handle the special education matter. … If the resource teacher misses the school for one day, then that class is not going to be run. (Resham, head teacher, focus group participant)* *Everyone, school administration, school management committee, school community, all tend to isolate the resource teacher. The resource teacher has become alone in the school. (Dambar)* *Some teachers are not willing to go near the children and care for them. They don't want to become close to them. (Bhadra, head teacher, focus group participant)*	**'They're different from us'**
Sanitation is also not good. Last time, she [her daughter] had wounds on her back. I took her home; it did not require any medicine for the cure at home. (Karuna) *No student is happy in the hostel. So, parents now do not let their children stay in the hostel. (Hari)* *The main problem is that the government establishes the special class and releases the budget. That's it. No one cares about it afterward. (Sukdev, former head teacher of a school with a special class for children with intellectual disabilities, focus group participant)* *There are no good facilities at the school. The budget allocated for the resource class is not enough. (Dambar)*	**Poor quality services**

Exemplifying quotations	Identified themes
I would be satisfied if he moves to the upper grades and completes his high school exam. But he has been in the same grade since he came here. (Tiru) *She didn't learn anything at school. She doesn't know how to brush or comb. (Shivani)* *School did not focus on practical skills such as making envelopes, candles, incense sticks or matchsticks. School should not give them a course book and ask them to go through that. That is not going to work. (Biswa)* *Parents of children with disabilities ask us to promote the children to the upper level. If there were more teachers, we would have put them in the proper grade level. (Sukdev)* *Up to what grade are they going to study in the school; where to send them after completing their education? Schools don't have plans for this; the students are staying in the same class for years. We need to have a different curriculum for them, but there is none. (Dambar)*	**Parents' expectations of schooling**
After Saput was enrolled here, there were no such meetings for parents. I think, maybe we are not required to come to the school. (Tiru) *Our child hasn't been to the school for many days now; but, you see, the school doesn't inquire about it. They don't ask us, 'why is your child not coming to the school? They don't bother to call us. There is no parent-friendly environment and support for us in this school. (Parent, Interview 11)* *I would just come to that place (points towards hostel with his finger). I would see the sister [aaya] there, leave my daughter and go home back. I haven't been to there (pointing towards classroom). (Choudhary)* *I don't need to do anything [when I come to the school]. I won't be asked to do anything in the school. (Narayan)* *Our children have been living here together for many years. I wish I had a chance to meet them [other parents], but I haven't seen any of them yet. (Karuna)* *I haven't met anyone here. I haven't been called to do that till today. (Prakash)*	**'No parent-friendly environment and support for us'**
In a meeting [in the school with teachers], we were informed that the government stopped releasing funds for lunch. The head teacher sir told us this. But I did not understand everything. (Kushal) *I would just sit and listen to them. Teachers would speak, and we would sit on chairs in front of them and listen to them. (Sarita)* *We would just listen to the teachers discussing who is going to be the chair and deputy chair in the committee, and so on. When someone wishes to run for the chair, he/she would request our votes. Mainly those types of things are done in the parent assembly. (Anish)* *Teachers need to consult with parents on various occasions, such as, if teachers want to prepare a plan for children with disabilities, the consultation with parents is beneficial. However, this is not happening in schools. [Leela, regular class teacher, focus group participant]*	**Lack of two-way communication**

Exemplifying quotations	Identified themes
We talked about our problems, but I don't think that [teachers] they would listen to us very carefully. (Shivani)	
If we [parents and teachers] could meet and talk to each other, we could give advice and have a mutual consultation. (Prakash) *I will come and discuss with the school people. It is for my child's future. I may lose something today, but I know my involvement here pays back later in the future. (Narayan)* *If we are asked for any type of support by the school, such as if they are building a house or rooms or if there is any other work and if teachers say, 'let's do it'; we won't say 'no'. (Miya)* *If the current school had invited me, I would have been able to explain to the other parents how we can help our children do these things [how to teach children basic things like combing, bathing, dressing, etc.] at home. I learnt some skills when I was abroad. (Kushal)* *Every parent wants to do their best for their children. Parents know many things about the nature of their children. Then the teacher knows the technical things – about teaching, education and so on. When they join hands and work jointly for the benefit of that child, it will be incredible. (Ravi)*	**Parents keen to be involved in schools**

Table 5.1 presented a total of 19 themes based on the exemplifying quotations from the stories of the participants in this research. The first nine themes were found to be related to participants' experiences and insights regarding raising or seeking cures for their children (Stage One of the parental journey) and the remaining 10 themes were related to the parents' experiences when they were trying to connect with the schooling of their children with disabilities (Stage Two of the parental journey). The next section of this chapter expands the themes grouped under these two stages, unfolding the parents' journeys of caring for their children with disabilities and attempting to connect with their schooling.

5.3 Unfolding the parental journey of caring for and schooling their children

This section revisits the themes introduced above in a series of narratives with a view to expanding and exploring their underlying meanings. The headings in this section are directly connected with the themes identified above and are organised in two main stages to reflect the unfolding journey of parents caring for and connecting with their schooling. Both stages relate to parents' experiences, with the addition of the perspectives of professionals in Stage Two.

Under each heading some background information is provided along with illustrative extracts and quotations. In this section, participant quotations are identified either by parent interview number or focus group respondent number only with a view to maintain the flow of narratives under each theme. A number of significant quotations that have already appeared in the in-depth portrayals in the previous chapter and Table 5.1 reappear to include the authentic voices from participants, as the relational approach to research emphasises the importance of the voices of participants/co-researchers (Finlay, 2009; Finlay & Evans, 2009).

5.3.1 Stage One: The stage of uncertainty: Birth, belief and search for a cure

The stories collected from parents for this research about raising their children with disabilities revealed much uncertainty, as their traditional cultural and religious beliefs came into contact with more recent medical and sociological perspectives on disability. This uncertainty is evident not only in how they viewed disability, but also in regard to their beliefs about its causes, and possible cures. Having a baby born with disabilities was itself a highly stressful beginning. As they moved further in this journey, they faced a myriad of challenges such as interacting with health services in the quest to find a cure, finding enough money to bear medical costs, seeking remedies and diagnoses, trying to identify a cause for their children's disability, and coming to terms with the reality of their situation. However, they did not only encounter challenges, but also experienced joy, surprise and pleasure. Stage One of their journey focuses on the years prior to school age, while the parents' experience of attempting to connect with their children's schooling and views of education professionals are the focus of Stage Two.

A stressful start: The birth of a child with a disability

The birth of a new baby in any family is generally a time of joy and thanksgiving. However, parents of babies with disabilities in this study faced considerable uncertainty. They shared that they were aware early on that their children had some difficulties, but that it took a long time to realise they had a disability since they had different perceptions about 'difficulty' and 'disability'. Initially, they believed the difficulty was temporary and therefore curable; only after the medical diagnosis did they come to know and begin to accept that the difficulty in their children was there to stay. Learning about their child's permanent disability was difficult to bear and, in most cases, there was much uncertainty. For example, a mother of a 20-year-old girl with an intellectual disability recalled how she first came to know about her daughter's disability:

> *We did not know it immediately. We thought that everything would be okay after some time. I took all the vaccines and injections while she was in the womb. After her birth too, she was provided with all types of vaccines and nutrients. … She was about two and a half months; we came to know that she was not quite normal. (Parent, Interview 12)*

Another mother, whose child had a hearing impairment, was confident, initially, that her son with a hearing impairment would talk when he turned two, because her eldest son started talking at that age. It is quite natural that parents always expect the birth of a 'normal' and healthy child and so they rarely plan for any adversity. When the parents found that their child was not 'normal' or had a disability they were shocked. In most cases, parents stated that people in their communities and neighbourhood would often describe their child by a label such as '*laato'* meaning 'dull' or 'simple', which added even more to the suffering of the children and parents. A parent in an interview expressed how distressing it was when people called her grandson by a label:

> *It is so depressing to hear that word 'andho' [blind] from other people. … If we were to make a child by our own wish as we make a pot from mud, we would have made him one of the best pieces in the world. (Parent, Interview 8)*

Parents in this research also spoke of how their children were often scapegoats and blamed for no reason. Their children were often exploited because they could not speak up for themselves. Parents reported that they felt hurt when other children were blamed, exploited and manipulated. As one parent of a child with a hearing impairment put it, 'they do not argue but rather tolerate it' or 'keep such suffering deep inside them' (Parent, Interview 4). Despite their sorrow and distress, these parents did not give up the search for a cause and a cure for their children's disabilities.

Seeking answers

When these parents came to know that their child had a 'difficulty' of some kind or a 'disability', they spent time investigating the nature of the disability and what might have caused it. Some tried to find an appropriate label for their child's disability. The parents' understandings of the possible causes of disability had roots in both cultural/religious and scientific/medical beliefs. While religions tend to attribute the cause of disability to past sins or ill fate, science sees its cause in biological factors or genetically inherited conditions. The comment by one parent below reflects the importance of his belief in fate and its role in her acceptance of their situation:

> *He was born like this. The god creates some people okay, and others with a disability. (Parent, Interview 5)*

Similarly, a grandmother of a 19-year-old girl with an intellectual disability and an incurable disease of the tongue, expressed her view that her condition was the result of her '*grahadasha'* (ill fate) (Parent, Interview 10). Some parents such as the father of a man with a visual impairment believed that evil spirits or the discontent of his ancestors were the cause of his son's problem. Other parents thought that their own behaviour may be the cause, for example, a mother of a child with hearing impairment who thought that her husband might have been unfaithful to her while he was away from home (Parent, Interview 1). In another example, a father (in Interview 4) believed that breastmilk had entered his baby's ears as a result of his wife not taking enough care during breastfeeding, which caused infection in the ears.

Not all parents in this research, however, subscribed to traditional religious views. Some believed there were medical reasons. For example, the mother of a child with a visual impairment said:

> *I think it was due to that water [fluid], which was accumulated in her head [brain] – that made her scratch her eyes, which then made her blind. (Parent, Interview 7)*

One parent participant attributed her child's visual impairment to the lack of vitamins and medicines available to the mother who was living in a remote village. Other parents stated their belief that domestic violence was the cause of their child's disability, as reflected in the following comment from the grandmother of a 6-year-old boy with a visual impairment:

> *My daughter [the mother of the child with disability] did not take her meals on time. She starved for many days. Her husband beat her, hit her and raged very badly when she was pregnant. As a result, this child became like this. (Parent, Interview 8)*

Lack of physical and emotional support during pregnancy and delivery was also cited as one of the causes of disability, with some husbands feeling guilty even now about their neglect in this area, wishing that they had been more caring.

Interestingly, most parents, even when they generally accepted their doctors' opinions, denied outright any genetic cause, as there were no other cases of disability in their families, as evidenced in the following account:

> *I know there was no such person with this type of impairment in our family clan. I have investigated it. (Parent, Interview 15)*

The selected comments above suggest that disability is not a straightforward and simple concept for parents; rather it is intricate and complex. The parents in this research hold varied understandings of the reasons for disability, from cultural/religious and scientific/medical perspectives to domestic violence (or gendered explanations in the patriarchal society), lack of support and self-neglect. In such contexts, more in-depth and complex knowledge about disability is needed in order to understand parental points of view.

Search for a cure

After learning about the disabilities of their children, these parents put dedicated effort into searching for a cure. According to their beliefs, the parents tried worshipping gods, visiting temples, making and fulfilling vows to please deities and their ancestors, consulting *dhami-jhankris* (witchdoctors and shamans) as well as visiting hospitals for modern medicines. They tried many things for a cure, either what their inner hearts told them, or what they were told to do by their relatives, neighbours, experts or whomever they came across in their journey. When one thing would not work, they went on to try the next. The grandfather of an 8-year-old boy with an intellectual disability spoke of such experiences:

> *We took him to various places. No temple is left; we took him everywhere – Balaji Rajasthan, India; Sheela in Syangja; and many other places. We took him to Baisnudevi in Jammu Kashmir in India and only after then, he started to walk. … Baisnudevi temple possesses the power of the goddess. (Parent, Interview 11)*

The following account from a parent shows a commitment to traditional medicines, though they were not always successful:

> *One of my brothers suggested I pluck seven shoots of dubo [a small herb] early in the morning, grind them and feed him one spoonful per day for 20 days. 'That helps some children speak', he said. I thought that could help him. However, due to that, he fainted. (Parent, Interview 14)*

These parents indicated that the use of *heraune-phukaune* (traditional healing with mantras), *dhami-jhankris* (faith healers – witchdoctors and shamans) and *jadibutis* (roots and herbs) is widespread. However, these parents did not always follow only the traditional healing methods; they also tried modern medical options that were financially and geographically accessible to them.

> *We did a lot for her treatment. There is no place in Nepal we have not been. We have been to different places in India, too. (Parent, Interview 6)*

The experiences shared by participants in this research revealed that many of those who held cultural/religious beliefs about disability eventually found themselves prepared to try medical remedies, as part of their desperate search for a cure. The parental love and care for their children with disabilities pushed them to leave no stone unturned in the search for a cure, even though the medical worldview challenged their existing beliefs.

Getting a diagnosis

The parents' experiences indicate it took a long time for them to name the problem. Only a few parents knew the official diagnosis of their children. The grandfather of an 8-year-old boy with intellectual disability said:

> *They [doctors] call them magajian [related to brain] or susta [slow]. This means, a 20-year-old person with this disability has a mind equivalent to 2 years old. (Parent, Interview 11)*

Another parent stated:

> *They said that my daughter falls under a category named 'Down syndrome'. Children with Down syndrome have short fingers, hands and legs and also have a slow brain. (Parent, Interview 12)*

While some parents, mainly those who were open to the medical or scientific perspective, were able to eventually get a diagnosis of their child's difficulties, other parents did not even seek an official label for their child's disability because they had reached a stage of acceptance, as one parent stated:

> *We noticed early on that that he is not producing any sound, later we found he is not hearing. We then anticipated that he is not going to speak. (Parent, Interview 5)*

For some parents, their child's disability was not apparent until some time later. Proper diagnosis in a timely manner would have provided these parents more comfort. In any case they continued to seek cures for their children with disabilities, whether traditional ones or modern healthcare services. However, in many instances their financial situation precluded them from accessing those services.

'We can't afford that'

As described above, parents in this research put their efforts into searching for cures for their children. However, due to poverty, parents were limited in their capacity to travel, for example to either hospitals or services in search of a medical cure, or to temples for a religious cure. A few parents were able to journey to Kathmandu and some selected Indian cities for treatment. A parent of an 8-year-old boy shared:

> *When we took him to the hospital, the doctor said, 'If you put a machine in the ear, it would work. It may cost up to 15 lakh rupees [15,000 dollars].' But we couldn't afford the money for that. (Parent, Interview 1)*

Similar accounts made by two other parents also revealed that limited financial means acted as a barrier to finding a cure:

> *We tried our best to save it [her daughter's eye]. We are poor people; we are not able to take her to different places. We do not have a regular income; we all are at home, with no jobs. We do not have enough land. There are only two or three katthas [about 11,000 square feet] of land, which is hardly enough for the shelter. (Parent, mother of an 8-year-old girl, Interview 7)*

> *When he was nine months old, I took him to a place called Bahadurganj. … I was very poor, and I didn't have even five rupees [5 cents] with me at that time. Nowadays I have a small shop in a trolley. I have a small shed in the name of home. There is no other income from outside; no one is there to support me. … I cannot afford anything. I am a homeless person. All my children grew up in this homeless condition. (Parent, maternal grandma of a 6-year-old boy, Interview 8)*

These parents spoke of their inability to afford the hospitals suggested by medical professionals. They believed, had they had enough money to afford such facilities, their children's problems would have been fixed in time. The people in this remote area of Nepal lacked job opportunities and other income-generating potential; many were dependent on 'a small farm' for their livelihood. This indicates that, although cures may be available, they were out of reach of these parents due to their poverty and lack of opportunity to make an income.

Reality check

Some parents in this research were shocked when they first learnt that their baby had a condition which was untreatable. Most of the parents learnt this from healthcare professionals.

> *The doctor said, 'It is from birth, it is not a disease.' (Parent, Interview 3)*

Similarly, another parent of a child with visual impairment described how a doctor he visited explained the permanent nature of his son's problem:

> *The doctor said, 'This is how it is for his whole life. This problem does not have any medication or treatment. Even if you take him to America, there is no treatment for him.' (Parent, Interview 15)*

This was the time when the parents came to know that their child's problem was not a 'disease', but a 'disability'. Their initial belief about their baby's problem was that it was a temporary, and curable 'disease'. This belief faded away after the visit to the medical professionals. Their children's problem by then had become a ‘disability’, which was completely different, for these parents, from what they previously believed. When they learnt that their baby’s problem was going to stay for a long time or forever, it made them even more stressed.

Many parents expressed their disappointment after visiting medical professionals. Medical advice such as, ‘Better you keep her at home. Medicine is not going to work for her’ (Parent, Interview 3) caused the parents to experience great anxiety and stress. Some parents even questioned the expertise of the specialists. A mother of a 8-year-old girl with visual impairment commented:

> *According to the doctors’ suggestion, we decided to take her to India for an eye operation. … They did the operation. We were hoping that her eyesight would improve, but nothing improved. (Parent, Interview 7)*

Similarly, a brother-in-law of a 15-year-old boy with hearing impairment shared that he postponed the idea of further treatment, after their dissatisfaction with several years’ effort to find a cure:

> *We took him to Kanpur, Lucknow and other cities in India. Doctors suggested nothing. We are not taking him to any hospital anymore. (Parent, Interview 5)*

Many other parents had similar experiences. The doctor at the hospital persuaded the father of a 19-year-old boy with intellectual disability that there was no possibility of a cure and so no purpose in further consultation. And a mother of a 20-year-old girl with Down syndrome spoke of how she first came to know about her child’s disability. The doctor said that her daughter was not going to be a ‘normal’ child, which was not what her family was expecting.

All these parents described that they were disappointed by the response they received from healthcare professionals. A few parents, however, also experienced pleasant outcomes from being in the hospitals:

> *He could not move at home but after the treatment he started to walk. We were not expecting this much progress from him. (Parent, Interview 1)*

Such experiences enhanced parents’ hopes for the future. In their journey, the parents also shared their stories of visiting various places, including faith healers and medical centres, where they witnessed the suffering of other parents, which assisted them to accept their situation. In addition, some parents experienced a pleasant surprise, as described below, which also helped them increase their level of acceptance.

A pleasant surprise

Some parents described that, at one point, they were not hopeful about their children's survival. They were afraid that their children would die; however, fortunately and sometimes astonishingly, their children survived. For example, the mother of a child with hearing impairment described an event in which her son suddenly became unconscious and closed his eyes. She took him to a children's hospital, where a doctor indicated that her child was not going to survive; however he could continue treatment. Fortunately, after a couple of days, her son became conscious. She happily shared that her son has progressed tremendously. Other parents also shared similar happy outcomes:

> *My son has become like this [progressed so much] – it is a true surprise. No one believed that he would survive. (Mother of a 12-year-old boy with multiple disabilities, Interview 14)*

> *The doctor said that the child was not going to survive long and told us to go back home. The hospital was two hours' walk from our home. We left the hospital and waited as it was expected he would die soon, and we would bury him and go home. After two hours, he started to suck the glucose drops ... We were not hopeful that he would become what he is today. (Parent, father of a 19-year-old boy with intellectual disability, Interview 17)*

The parents experienced joy that their dear ones were still alive and doing well even though they had at one stage lost hope. This gave them the courage to accept and live with their children's disabilities and face the challenges. Gradually, they started to feel proud of their children and dream about their future, as described below.

'Feeling proud of our children'

Parents in this research generally felt pride and expressed their satisfaction when their children achieved certain milestones. With increasing knowledge about their children's disability, these parents also began to appreciate and admire their children for any success they achieved, no matter how big or small such successes were. The following statements from two parents, for example, suggest the pride they felt in their children's progress.

> *One day, we were having our breakfast at home. It was eight in the morning. There was a tractor to plough the farm. Dipesh [his son with a hearing impairment] went and drove the tractor. ... He ploughed the land, moving it over the muddy farm field. We all, including my father, mother and brother – watched it and felt happy about it. (Parent, Interview 4)*

> *He greets his father's sister or grandma by touching their feet. He has very good manners. (Parent, Interview 8)*

Other parents feel proud of their children's sharp memories and are satisfied with their children's performance at school. A few parents described their children as bright and capable of learning very fast. 'Something that is told once is enough' for them (Parent, Interview 5). Other parents were happy to listen to their children sing songs: 'She would sing the songs about children with disability that she learnt at school. She made us cry by singing those types of songs' (Mother, Interview 7). Another mother of a girl with Down syndrome was happy that her child could speak, call 'mother, father, brother, sister-in-law, uncle and aunt' and let her parents know that 'she is sleepy, thirsty, or her hair is messy, and she needs a bath' (Parent, Interview 12). Similarly, when the parents find their children are able to wash their clothes or go to the toilet by themselves, it makes them happy. Some parents felt pleased that their children did not 'go anywhere outside alone' or 'carefully watch for vehicles before crossing the road' (Parent, Interview 11). Some parents thought their children's positive behaviours, such as not bothering their neighbours by simply staying at home and watching TV, were admirable because such behaviours could ease their caring job.

Some parents also admired their children for helping with household chores. In some cases, they shared that their children's efforts even exceeded their expectations. Parents in a family interview described:

> *Bigul unleashes the buffaloes, takes them to the jungle, brings them back and leashes them again. Then he would also clean up the buffalo dung. (Parent, Interview 17)*

Parental feelings of pride in their children and their favourable outcomes, however, did not always provide joy and happiness. These parents felt despair from time to time, suggesting that they also underwent ongoing reiterative stress. Moreover, the cultural notion of gender in the society in which these parents were living was found to have differing effects on both female children with disabilities and female caregivers in their home.

The cultural face of gender

Some parents in this research made comparisons between having a boy child and girl child with a disability. They felt more distress and concern, if their child with a disability was a girl; it added more sorrow for them. Additionally, the parents expressed that being a female member of the family of a child with a disability leads to different concerns and expectations. Women undertook the roles of caregiving and raising their children, including those with disabilities, and compared to fathers, mothers of children with disabilities were more involved in such roles.

A mother said:

> *Yours is a son and mine is a daughter. She has to go to another's home after marriage. (Parent, Interview 7)*

Some parents in this research were concerned about how a girl with a disability would manage living in another's home, as girls, as a cultural norm, are expected to do. The brother of a 12-year-old girl with a visual impairment, who himself has a visual impairment, said:

> *There was already one child who is blind (that is me). But, I was a boy. Then there is the next child with the same condition, and she is a girl. ... In our society, the females have to go to others' houses when they get married. It was a big concern for our family. (Parent, Interview 6)*

The parents in this research were concerned about the safety of girls with disabilities, as they could not leave them alone, because 'Today's atmosphere is not good and safe' (Parent, Interview 12). Another parent shared: 'She is a girl. That makes us always stressed and cautious' (Parent, Interview 2).

In the community where this research was undertaken, being a female or male member of the family of a child with a disability meant different life experiences caused by the psychological, social or cultural expectations associated with gender, with the female members generally facing more hurdles and discrimination. Although both fathers and mothers expressed that they faced immense challenges in living with their children with disabilities, mothers shouldered extra burdens and struggled more. Mothers were the primary caregivers for children with disabilities, due to their traditional role in raising children. For example, the mother of an 8-year-old girl with a visual impairment gave an extensive account of her experiences of visiting doctors multiple times in a nearby city:

> *I took her to Bhairahawa Eye Hospital. At that time, one of her eyes was about to come out. They [doctors] put a lens in her eye. Then I came home; I went to plant the paddy, after a while her father came to the field and asked me to rush home. Her eyeball was swinging outside the eye. I cried a lot; then took her to Bhairahawa again – twice, on the same day. I wasn't accompanied by anyone. … There was no means of transportation from my home. I asked one of our relatives for a lift to the bus station. … While we were changing buses in Butwal for Bhairahawa, her eyeball fell out of the socket. It was tiny white ball. Although I thought that it was not going to work for her, I kept it in my bag. We reached the hospital and I told everything to the doctor. ... He admitted her and told me that he was going to do an operation the following morning. I stayed there that day. … [Doctors] cleaned [it], put a piece of flesh in the eyes and stitched the eye with a thread. Then we came home. From the*

> *next day, there was pus running from her eyes. My husband even blamed me for not treating her well in the hospital. (Parent, Interview 7)*

Participants' accounts revealed that the mothers' role was not limited to provide caregiving to their child with a disability, but that they alone were responsible for every household chore. A mother of three children, one with severe cerebral palsy, explained that she also has to care for her husband and two other children (Parent, Interview 16). She was constantly busy with household chores, which are the sole responsibility of women in Nepal, in addition to minding her son with a disability at all times.

Some mothers faced challenges dealing with officials to get their government entitlements. A single mother of a 5-year-old girl with multiple disabilities was not able to get a birth certificate because her husband did not register her birth in the government office:

> *Officials required a birth certificate to allocate the disability allowance to my daughter. I will get that birth certificate only if her father registers it for us. What can we do when her father is not supportive? For us, he is dead. (Parent, Interview 13)*

Male participants in this research also acknowledged that mothers of children with disabilities held more responsibility:

> *My wife dealt with everything including his education. When my son was enrolled at school, I was abroad for a job. … Now I work in the field until 10 or 11 o'clock at night. I am not free. (Parent, Interview 4)*

This indicates that, as well as the caregiving roles, exploring education options for their children with disabilities was the mothers' responsibility. In some cases, even grandmothers shouldered caregiving responsibilities of these children, as described by a father of a 19-year-old boy with multiple disabilities:

> *He would have saliva and snot all the time. Everything would be wet. His mother and grandmother (who is deceased now) shouldered a lot of the burden. (Parent, Interview 17)*

In addition, mothers shared that they had bitter experiences of even being blamed or scolded by their male counterparts. The grandmother of a 6-year-boy with a visual impairment, who was taking care of her grandson, stated how she was offended by her son-in-law:

> *When he meets us, he starts to scold and threaten us; he gives us warnings that he is going to behead us. (Parent, Interview 8)*

To conclude, parents in this research underwent periods of great uncertainty after having a new baby with a disability. This section relates to one of the sub-questions of this research: How do parents describe, understand and feel about their experiences of caring for and connecting with the schooling of their children with disabilities in a western region of Nepal? The study has found that the birth of babies with a disability signals the start of a difficult life. Initially for the study participants there was huge sadness as they did not understand the nature of the problems and what caused them. After passing through this initial stage of uncertainty, the parents searched for reasons for their children's disabilities. They held differing and sometimes conflicting views in regard to the possible causes of their child's disability. Views about the causes included past sins, misconduct, unfaithfulness, malnutrition, and lack of support during pregnancy or delivery. In many cases, while they accepted doctors' opinions about the cause of the disability, they ruled out genetic causes.

Parents sought out traditional remedies such as roots and herbs and visited faith healers. They tried more modern medical treatments as well; however, they could only access treatments and facilities they were aware of and that were geographically accessible and within their financial capacity. They were shocked and distressed when they finally learned that the problems their children had were permanent. This was a time when they experienced a loss of hope. By attributing the cause of suffering to religious belief and with exposure to other parents' suffering in similar circumstances, they gained greater ability to face their children's disabilities. They gradually demonstrated increased awareness and levels of knowledge about disability and began to appreciate the positive aspects and abilities of their child. This acceptance, however, did not always result in a blissful life; they still felt sorrow and despair from time to time. Female members living in the same circumstances appear to have experienced more unhappiness than their male counterparts. The parental journey of living with their children with disabilities began a new stage when they started to think about schooling options, and their experiences during this stage are discussed in the following section.

5.3.2 Stage Two: The stage of disappointment: Hope, schooling and untapped potential

This stage represents the experiences of the parents of children with disabilities as they attempted to connect with their children's schooling. Information gathered from interviews and focus groups participants supports previous research detailed in Chapter 2 that education is not easily accessible for these children. It is evident from the data gathered for this research that most parents and professionals value education very highly as they believe it creates an opportunity for a better life; however, many of the children with disabilities remain out of the schooling system. Moreover, although these parents care for their children, want the very best for them, and are prepared to make a contribution to the schooling of their children, they have not been given an opportunity to be involved in their child's education.

'Nothing is more important than education!'

Most of the parents saw great benefits in educating their children with disabilities, but since they were generally not able to send their child to the local school they needed to look further afield. Despite their deep affection for their children they were prepared to send them to a school with hostel-style accommodation. To quote the grandmother of a child with intellectual disability, living in Kapilvastu which is 350 kilometres away from Kathmandu, 'For the child's future, we are ready to leave him in the hostel, even in Kathmandu' (Parent, Family interview 11). Similarly, another mother showed her eagerness to educate her daughter under any circumstances:

> *Even if it [the school for children with visual impairment] was available only in Kathmandu, I was thinking of sending her there for study. I was telling family members that 'We should send her to school; we should not keep her at home, for she cannot see.' Nothing is more important than education. (Parent, Interview 7)*

For another participant, his growing concern about his son's future pushed him to send him to school. 'What will happen tomorrow, if we don't send him to a school? If we just keep him with us at home, we will spoil his future' (Parent, Interview 4). He feels that parents should not become too attached to their children because: 'If you love them very much now and keep them at home, their future will be ruined.' For the sake of their children's education and future career, these parents were ready to send them far away and bear the stress of leaving them in schools. For example, 'Even if he recognises the alphabets, it's good' (Parent, Interview 1). Education and the school experience were so important for these parents that they did not even stay long when they went to visit their children at school hostels. One parent said:

> *I would stay only for 10 to 15 minutes and then leave, because if I would stay longer, he may want to go home with me. (Parent, Interview 8)*

These parents clearly placed great importance on education. They wanted to see their children with disabilities sitting, playing and mixing with children *without* disabilities in schools. Being together with their friends without disability, as described by a parent, they can learn many things and they learn them much faster (Parent, Interview 1). For some parents, it was school that for the first time provided their children with an opportunity to know others and make friends. The brother-in-law of a boy with hearing impairment highlighted the benefits of being in school. In his opinion, these children can learn things by seeing and interacting with each other. 'They learnt what to do and not to do. They also feel proud that they are studying in such a big school' (Parent, Interview 5). As illustrated below, parents in this research gave more emphasis to their children's education and career building than their own emotions:

> *My husband says that 'Sabina has become thin and weak being in the school hostel, and she also got head lice. The school's sanitation is not good. So, better not to keep her there.' I would then say, 'It is certainly difficult for her to be in the school, but we should not be worrying about our kid's thinness. The accumulation of flesh in the body is not a big deal; the main thing is her education.' (Parent, Interview 7)*

Parents who had not had an education themselves regarded education positively. The mother of a 5-year-old girl with intellectual disability stated that, despite the fact she did not have a chance to study, she thought that her daughter should study more (Parent, Interview 13). As her daughter was not able to speak, she took her daughter to the school when she was two, with the hope that she would mingle with other students and be able to speak. Similarly, another parent thought that education for children with disabilities was more important than for their counterparts *without* disabilities:

> *Rather I would think if children without disabilities are not able to do well in their study, still they could make a living. They can plough their land and manage to make ends meet. But, who would feed these children who have visual impairment? If they get education, they can do something. (Parent, Interview 9)*

Parents' positive views about their children's schooling were supported by the professionals during the focus group discussions. A teacher recalled a parent saying: 'I should provide an environment so that my child would be able to learn something or become something' (R1, Focus group 1). Both parents and professionals in this research placed significant importance and positive value on education. Parent participants in this research valued education so highly that they were ready to make sacrifices for the schooling of their children. They were even ready to put them in hostels, even if they were likely to miss their children terribly and even if their children were unhappy or unwell there.

Inspiring role models

For some parents in this research, their belief in the power of education came from seeing that some people with disabilities had achieved a certain level of success, for example they found that a remarkable number of people with disability became teachers. Many parents referred to people with visual impairment becoming teachers in their locality, which served as a role model for their children. A parent said: ‘Look! The sir here [a teacher with visual impairment in her daughter’s school], he struggled a lot, and now he is a teacher’ (Parent, Interview 7). Another parent was also influenced by the success of his grandson’s teacher:

> *When I saw the teacher [with a visual impairment], I become more hopeful for my grandson. … He [the teacher] is doing great; he manages the school; he teaches our children. Then I thought why couldn’t my child become like him? (Parent, Interview 8)*

Parents in this research did not only find role models in their local area; some parents learnt from the media about the successes of people with disabilities. A parent spoke of the example of Parijat and Jhamak Kumari – two iconic figures in Nepal, both females with severe physical disabilities, who reached the pinnacle in their fields (both in Nepali literature, as mentioned in Chapter 4) (Parent, Interview 6).

Many parents admired teachers who supported them to find a school for their children with disabilities, indicating that teachers (mainly those with disabilities) served as role models. A mother of a girl with a hearing impairment, in search of a school, visited two residential schools in the district before she finally came to know about the right school for her. It was a teacher with a physical disability who had informed her about the school (Parent, Interview 2). Other parents, such as the grandmother of a girl with intellectual disability and the father of a girl with a hearing impairment, also appreciated teachers visiting their homes and informing them about the availability of schooling options for their children (Parents, Interviews 4, 10).

Some parents also spoke of efforts made by head teachers and resource teachers to locate children with disabilities and convince their parents to send them to school (Parent, Interview 6). The participants in focus groups also confirmed this when they told of their experiences of teachers convincing parents to consider sending their children to school. A former resource teacher, for example, said that initially, when the parents were not ready to send their children to school, he went to visit them. He was accompanied by a child who knew sign language. He told the parents, ‘This child has a similar problem to your child; and now he is able to do this and this’ (R2, Focus group 1). When the parents saw the child, they realised that their child could become like him. The parents were motivated by seeing an example in front of them. They thought, ‘If he is able to read and write, why not mine? I will also send my child to the school’ (R2, Focus group 1). In such cases, students with disabilities, peers of their children, served as role models.

'I can see a huge difference': The benefits of schooling

Some parents expressed the benefits for their children of being in school. A mother noticed: ‘She learnt to read and write in the school, previously she did not know anything’ (Parent, Interview 2). For these parents, schools have catered for their children’s educational needs. One parent described:

> *He did not know anything before, now he has learnt sign language, and can communicate with teachers and other children with hearing impairments. (Parent, Interview 1)*

Other parents observed the change in behaviour of their children, in addition to their academic progress, after being in school. One parent described:

> *She [now] behaves completely differently. She has learnt plenty of things … I have two other children at home, but they don’t write as nicely as her. (Parent, Interview 3)*

Similarly, another parent believed the school helped improve his son’s conduct. ‘Playing, stealing, fighting; that’s what he would do at home, before coming to the school. Now he is far better’ (Parent, Interview 4). Parents in this research also related the acquisition of basic skills such as ‘finding the way to the school’ (Parent, Interview 5) by themselves as a measure of the success of schooling. This parent described:

> *I can see a huge difference, like the difference between earth and sky in our child before coming to school and how he is now. (Parent, Interview 5)*

Some parents, especially those from a linguistic minority (who represent an indigenous group from *Terai*) such as the father of a boy with visual impairment, were happy about their children’s schooling because they learnt the mainstream language:

> *The first thing is, he is now able to speak Nepali clearly. Even I am not able to speak as clearly as him. (Parent, Interview 9)*

Some parents thought that, because of schooling experiences, their children can envisage a future career. In a parent’s words: ‘I am happy because she says that she wants to become a *thulo manchhe* [a great person] in the future’ (Parent, Interview 6). Due to schooling, the parents and families were found to be hopeful about their future.

Many parents credited school staff, such as resource teachers and *aayas*, for the progress their children had made from being in school, even for a short period. ‘Teachers here have done a lot to make change' (Parent, Interview 8). The father of a boy with intellectual disability similarly expressed satisfaction with the teachers' roles:

> *We have heard that there were many cases of students with disabilities being teased by other students with higher mental ability. However, in our case teachers truly watched everything and prevented that sort of activity. So, it helped him a lot to develop his skills, just because he went to the school regularly. He managed to go to school with his 1000 fellows. He went to his classrooms by himself. Teachers seated him on the front bench. That all helped him greatly. (Parent, Interview 17)*

In one case, teachers permitted a young girl to go to school even after the official age, as described by the parent of a 20-year-old girl with Down syndrome: 'Last year, initially the school asked us not to send her to the school, because of her age. Later they decided to continue her in the school. The madam [teacher] did us a favour' (Parent, Interview 12). In some instances, head teachers proved to be very helpful, for example, contacting the parents of a child turning six and inviting them to enrol him in the school (Parent, Interview 8).

The support and services their children receive at school hostels and from *aaya*s were satisfactory to many parents. 'The *aaya* madam is a very caring person. She cares for the children as if they are her own' (Parent, Interview 1). The *aaya* would even 'provide her own bed for the children to sleep in', and the children were happy in hostels and they even cried when their parents came to take them home (Parent, Interview 2). The facilities provided in the school hostel also appealed to some parents.

> *The meals provided here are good, nutritious; this is better than what we could offer them at home. (Parent, Interview 9)*

The father of a 14-year-old girl with a hearing impairment recounted her daughter's school life: 'Breakfast in the morning, food, showers two or three times a week, clean hair' (Parent, Interview 3). Parents in this research also reported that *aayas* and school teachers did not want parents to take their children home very frequently. A parent referred to a teacher saying that if parents take their children home every week that may spoil the children and they may not progress well in their studies (Parent, Interview 5).

Some parents in this research viewed even the average level of facilities as adequate because their children had disabilities. 'Living in there is OK. Our children themselves are like that. They do have their own problems' (Parent, Interview 4). These accounts from the parents indicate that they did not demand a very luxurious life for their children at the hostels. A few parents, particularly those who themselves had disabilities, compared the current facilities to those of their time:

> *I didn't get any braille book up to grade 8. I completed grade 7 without any book. … It would take years to revise the books according to the curriculum. But these days, if the curriculum changes, the government publishes new books in the same year*. *(Parent, Interview 6)*

Participants of the focus groups had observed some visible changes in educational provision for children with disabilities. They credited the recent initiatives of the government for this change. A teacher in one focus group noted:

> *We can see the effect now in those schools; all types of children have started to play together; walk together; eat together. Through these activities, they started to learn from each other. (R2, Focus group 1)*

In addition, focus group participants spoke of the change they observed in the perceptions of children without disability. They developed positive attitudes towards their peers with disabilities, as they were together in the same class and in the same school. They would realise their peers' difficulties and become ready to communicate in sign language or other ways the children with disabilities could understand. Also if their peers are not able to see, they would hold their arm and lead them to places they needed to go.

The remarkable result of educating children with disabilities, according to these participants, was that students were given the opportunity to learn to respect each other, socialise, and acknowledge their differences, which significantly benefitted the children with disabilities. This was possible because of the establishment of resource classes within the general school premises (R2, R5, Focus group 1; R13, Focus group 3). Further benefits of schooling reported by the participants in the focus groups were the positive change in people's attitudes towards disability, and the freedom for the parents to engage in other household chores.

In contrast to the observations described above, the experiences of the parents and professionals regarding the schooling of children with disabilities were not always pleasant. Participants explained that these initiatives were not enough to cater for children with disabilities, and were not well-organised, welcoming or disability friendly.

A lack of welcome for children

Several participants experienced instances where their children were denied school enrolment. As we saw from the case-focused in-depth portrayal of Sheetal, her son was denied admission to school because he is incapable of doing minimal things like going to the toilet by himself (Parent, Interview 14). In other cases, such as when parents have a child with a profound disability, they described that they were not approached by anyone with a proposal of any schooling option. The mother of a boy with severe cerebral palsy said: ‘I haven’t gone anywhere to inquire about school, as no one came to me and suggested school for him’ (Parent, Interview 16). A grandfather of an 8-year-old child with intellectual disability faced such a problem:

> *The teacher asked me to bring my child to the school only when he turns 10. He said, ‘Your child is small now; the big children will abuse him and beat him. By that time, this child will grow to a level to be able to stay here without family.’ (Parent, Interview 11)*

Some parents in this research had difficulty finding the right school due to the competence level of their children not matching that of other students. For example, a child with an intellectual disability was refused by two schools his father visited; by the first school (a mainstream school) because he did not fit with the ‘high-ranking’ students and by the second school, which was running a special class for children with intellectual disability, because ‘his level was very high compared to other students’ (Parent, Interview 17*).* The schools labelled this child as smarter than other students with disabilities but less smart than the students of the mainstream school.

Teachers in the focus group accepted that children with disabilities were not easily enrolled in school. A former teacher of a special class, who also has a physical disability, said:

> *The first response of most schools will be ‘We are not able to teach your child. This is not a school for your child.’ That’s how parents would be treated in the beginning. The school would harass them. School professionals won’t explore what the child can learn or any possible place for him/her. They just ignore them. (R2, Focus group 1)*

Other teachers responded that, with the current level of resources available in schools earmarked for special education classes, they are not able to enrol children with severe and profound disabilities. A teacher in the focus group suggested parents seek other options:

> *Teachers [in such cases] should inform parents about the facilities offered by the government such as the identification card and the rehabilitation centre. The teachers should learn about all these facilities and inform parents so that they can take their children to those places. (R3, Focus group 1)*

Even if their children were enrolled, parents in this research did not always find school a welcoming environment. The father of a child with hearing impairment explained: ‘Teachers would just say, “Other kids are complaining about your son that he has done this, and he has done that; it would good if you do not send him to this school”’ (Parent, Interview 4). Moreover, discrimination persisted in the form of isolation or isolating attitudes towards the children with disabilities and even towards their parents, teachers or classes.

‘They’re different from us’

It is evident in the data that children with disabilities, their parents, their teachers, and even the classes where these children were taught, were treated differently. They were considered separate from what is seen as ‘normal’. Participants, mainly teachers and professionals from the focus groups, spoke of how special classes continued to be perceived as different from the mainstream classes:

> *In most schools in the country, it is thought that the special education class is not part of the mainstream school. It is different because it is for children with disabilities. It is separate because there is a separate classroom. There is a separate teacher and so on. (R2, Focus group 1)*

The attitude of general stakeholders towards disability, as described by the participants, also isolates special education classes and children with disabilities. Consequently, special education teachers are left alone to deal with special education issues. The same teacher added:

> *Everyone, school administration, members of the school management committee, school community, all tend to isolate the resource teacher. She/he becomes alone in the school. The children are barred from learning diverse things, which they would otherwise have learnt. That practice still exists in the schools. (R2, Focus group 1)*

Another mainstream teacher agreed with this view, saying: ‘Other teachers don’t care. “It is their [resource teachers’] responsibility”, that’s what other teachers think. This thinking might not be intentional, but it has developed in that way’ (R6, Focus group 1). A head teacher from another focus group observed: ‘If the resource teacher misses school for one day, then that class is not going to run’ (R7, Focus group 2). Another head teacher had a similar experience:

> *If we give all responsibility only to the resource teacher, that won’t be helpful to achieve our objectives. However, it depends on the nature of our staff. Some teachers love kids, they put the kids in their laps and kiss them. Other just don’t care about them and do not go near them. (R11, Focus group 2)*

School administrators sought the advice of resource teachers for all matters concerning students with disabilities including their activities, classes or grievances. However, some participants showed their disagreement with this attitude:

> *The efforts of resource teachers alone won't be enough; every staff in the school should be equally supportive of these children. So, we need to be more active, otherwise we will not be truly providing the stipulated support for the children, on behalf of the government. (R9, Focus group 2)*

Some participants reported that even the overseeing agencies, such as government officials, tend to overlook these classes. A teacher in a focus group said, 'The District Education Officer would only observe the mainstream classes – not the special education class, if they visit the school' (R19, Focus group 4). He spoke of a culture, which he thinks developed after the 1990s (after the restoration of democracy in the country), in which people attend more, or only care or inquire about, those groups who can exert pressure. If any group does not or cannot put pressure on the authorities, then it is likely that that group will not receive enough attention.

The ways these schools operate currently suggests that their efforts are limited to the physical integration of the children with disabilities in the school and not the genuine inclusion of these children. Schooling for children with disabilities is not yet accepted by the existing system as part of mainstream schools and hence is still isolated. In addition, the services and facilities at schools targeted to these children generally are found to be sub-standard.

Poor quality services

Many parents spoke of the quality of the available services being poor for their children with disabilities. They were concerned particularly about food, hygiene, toilets and sanitation, and the sports equipment in their children's hostels. They complained about government indifference towards the poor facilities. A grandfather expressed his concern about the meals provided to his grandchild at the school hostel:

> *He [his grandson] needs milk in every meal. Who would provide him milk every time? He likes chapatti rather than rice. Who would bake chapattis for him? Therefore, he does not want to live in the hostel. (Parent, Interview 11)*

A mother complained about the unsanitary conditions at the hostel:

> *The toilet is not clean here. Last time, she [her daughter] had wounds on her back. I took her home. It did not require any medicine to heal – it was because of the sanitary situation. (Parent, Interview 7)*

A parent from another school had a similar experience:

> *The toilet was terrible, it was so dirty that you can't even imagine. … Our kids do not know anything, but such problems shouldn't be underestimated. (Parent, Interview 11)*

Many parents in this research compared the hostel facilities with other schools' facilities and expressed their desire for their children's schools to improve the conditions: 'I have seen the hostels of other schools too. Some hostels are good, and some are not. Those that are not good should be improved' (Parent, Interview 6). A mother stated: 'I think, for the betterment of the hostel, rooms should be neat and clean. Rooms should be properly managed for sleeping, living, studying and dining' (Parent, Interview 2).

Some parents also spoke of a lack of sports equipment for their children at the hostels. A mother, for example, stated: 'If children do not want to read and write after the meal, they would only sit. There is nothing to play with' (Parent, Interview 2). Another parent spoke of why his child's hostel is closed now: 'No student was happy in the hostel. So, parents now do not let their children stay there' (Parent, Interview 11).

However, government officials in the focus group opposed these views of the parents and even blamed parents for being greedy:

> *They demand the incentives they are entitled to. They are happy to get money in cash instead of keeping their children in the hostel. (R19, Focus group 4)*

However, this view from focus group participants contradicts the eagerness expressed by many parents to send their children to the school, as discussed previously. The value parents place on education exceeds their desire to keep their children with them at home.

Some participants in the focus groups believed that the services and facilities for special classes were not adequate, even though the government was intervening positively to address the needs of children with disabilities. The following quotation from a head teacher explains this contradiction:

> *The main problem is that the government introduces a new program, such as special classes in the mainstream school. It also releases a little budget. That's it. No one cares about it afterwards. (R12, Focus group 2)*

The ad hoc nature of government initiatives, in which programs are launched without enough preparation and without thinking of their sustainability for the future, was also highlighted in a focus group discussion. A former resource teacher, now an activist working in the disability area, said, ‘The government doesn’t focus on making the program organised’ (R2, Focus group 1).

The main reason given for the lack of facilities at the schools and hostels was financial. The schools were under-resourced to build disability-friendly environments. A head teacher expressed that poor enrolment and poor access to education for children with disabilities was due to inadequate facilities:

> *Where is the disability-friendly toilets? Maybe there are some toilets being constructed these days for students with disabilities, but there are none in the older schools. (R12, Focus group 2)*

A parent of a child with intellectual disability observed that the poverty of the whole nation was the main cause of the government’s inability to fund schools adequately. He said:

> *The government is poor and cannot afford much. This is the problem. Once, I was talking to the aaya in the school about the facilities for these children; she said, ‘We haven’t received our pay checks for the last six months; what can we expect for these children from the government’ … There are very good systems abroad. Apart from the government, there are other agencies supporting people with disabilities. In Nepal, we are poor; there is mounting poverty. (Parent, Interview 11)*

A head teacher also stated that schools are poorly funded to build disability-friendly infrastructure. He recalled an instance of school construction:

> *There was forty hundred thousand rupees [about $40,000] to construct a four-roomed building in our school with a ramp. All the toilets were old fashioned. We needed to construct the toilets. Then comes the ramps to the toilets. Tell us, how would we be able to make ramps to the toilets too with that amount? (R12, Focus group 2)*

The head teacher further emphasised that disability-friendly schools are not enough; that a disability-friendly society is needed to cater for these children’s needs in a true sense. He explained that, even if a school could make ramps, children would not be able to come to the school if they do not have ramps all along the way to the school from their home. In such situations, he satirically questioned, ‘Should a school be expected to make ramps in the roads as well?’ This indicates the lack of coordination between schools and other agencies such as the authorities related to civil construction, let alone lack of social planning and inadequate funding.

Parent expectations of schooling

Many parents clearly articulated their concerns about the learning of their children. Even though their children had great challenges before them, their parents still aspired to academic excellence. They clearly valued schooling and wanted their children to study more and to progress to higher grades and apply for further studies.

Many parents thought that their children's academic needs were not met by the schools. Their focus on academic success was evident in examples such as:

> *I would be satisfied if he moves to the upper grades and completes his high school exam. But he has been in the same grade since he came here. (Parent, Interview 8)*

The completion of the high school exam, which is now known as the Secondary Education Examination (SEE) in Nepal[22] is a matter of pride for children and parents. When their child completes this milestone, Nepalese parents feel that a life goal has been met. It is perceived as the gateway to enter higher education and jobs. A head teacher during a focus group commented about what parents aspire to for their children:

> *Parents of children with disabilities ask us to promote their child to an upper grade. If there were more teachers, we would have put them in the proper grade level. (R12, Focus group 2)*

This again is linked to the shortfall in resources at the school level, as discussed in the previous section. Another participant in a focus group admitted that there is no grade promotion or transition plan for these children:

> *Up to what grade are they going to study in the school; where do we send them after completing their education? Schools don't have plans for this; the students are staying in the same class for years. (R2, Focus group 1)*

Teachers and head teachers also perceived some of the parents' expectations as overly ambitious. A head teacher stated:

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[22] Previously this examination was famously known as the School Leaving Certificate (SLC), which was instituted in Nepal in 1934. In 2017, with the new structure of school education, the name of this examination was officially changed to SEE. Most people in Nepal continue to call it SLC in general or informal use.

> *We always talk from an idealistic perspective; we never want to know the realities on the ground – the difficulties schools are facing. I think the 'ism' that is most associated with failure in the world is idealism. (R12, Focus group 2)*

Another head teacher commented that parents do not take much care to find out about their children's condition and they are not interested in obtaining information from around them as they do not know if these schools exist in their community (R7, Focus group 2). During the follow-up visit also, a teacher, who was also a participant in the teacher's focus group, said that parents in general are very demanding (R3, Focus group 1).

In addition, many parents did not acknowledge their children's other types of expertise or intelligence beyond the academic ones:

> *I feel bad when the teacher calls and tells me that my daughter does not focus on her studies, rather she has an interest in songs and music. Then I would tell him, 'Please don't say that and please help her focus in her studies.' (Parent, Interview 7)*

Parents in this research wished their children could be promoted to an upper grade, complete a certain level of education and secure a place in higher education, which can be attributed to their desire for academic excellence. However, while most parents strived for academic success, a few parents expressed the importance of learning social and practical skills in school. The mother of a girl with Down syndrome observed the lack of instruction in basic practical skills in the current school. However, she was satisfied with the skills that her daughter acquired in the school she attended previously when she and her family lived abroad:

> *There, not only the children were taught, we parents were also trained about what to do at home; what to teach them at home; what to do while feeding and while sleeping; what to do while sending the child to school; how to teach them to brush their teeth, how to not make a mess while eating and so on. Then we did accordingly. She might not have learnt to read and write well; but those activities at that school helped her a lot. (Parent, Interview 12)*

She further suggested the current school should do such activities, as they were very beneficial to both children and parents. Some parents expressed that practical skill-oriented courses and subjects that interest the child are important for consideration. The father of a 19-year-old boy with intellectual disability stated:

> *The bookish knowledge is not that important. School should not give them a course book and ask them to go through that. That is not going to work. … School should focus on practical skills – making envelopes, candles, incense sticks or matchsticks – that may interest them.*

> *They can be provided with a big blunt needle and ask to sew sacks. They probably can do it. They can make balls from clothes but cannot grasp the academic courses. (Parent, Interview 17)*

He also indicated that it would be good if the school identified the main areas of interest of children with disabilities and proceed accordingly, rather than just focusing on academic aspects. He further added:

> *If you allow them to grow in their area of interest, they will do their best. Everyone, no matter what type of disability she/he has, is able to do their best at least in one area. (Parent, Interview 17)*

A resource teacher in the focus group stated that schools should be aware that the content of books is not the only knowledge. Teachers should try to develop a range of practical skills in students. Extracurricular activities such as dancing, music and putting clothes on are all parts of education (R2, Focus group 1). Other teachers agreed with this and argued that curricular goals for the children should be as simple as these:

> *If they are able to take a shower by themselves; if they can do personal hygiene properly; if they can put on their clothes by themselves; if they can do up their buttons; if they use toilets properly; if they can clean their hands and mouth after meals; that's fine. These should be the objectives of their study. This should be their degree. (R5 and R6, overlapping voices, Focus group 1)*

A 14-year-old child with a visual impairment who attended the interview with his father showed his interest in media anchoring:

> *I have already conducted a child's program named 'Voices of Children' on an FM radio station. So, I am interested to learn something in the radio sector along with my study in the school – without losing anything in my study. On Saturdays, there is no class. Therefore, I can utilise that time for it. (Interview 9)*

The child emphasised this matter because radio anchoring was not considered a part of the school program. This indicates that children's interests were not addressed in the school; rather the school focused on the traditional three Rs (reading, writing and arithmetic); it did not focus on multiple intelligences (Gardner, 1992, 2000). A resource teacher admitted that 'We need to have a different curriculum for them, but there is none' (R2, Focus group 1). However, the problem many focus group participants mentioned was that there is a general assumption that teachers should impart academic knowledge to all children regardless of their interests. For many parents, education is what is written in books alone. This is mainly a curricular issue; there is a lack of specialised curriculum that would cater for the needs and interests of children with disabilities.

'No parent-friendly environment and support for us'

Information gathered from parents indicated they often did not feel welcomed by their children's schools. Although many parents held the view that their engagement in the schooling of their children with disabilities was crucial, they were never or only rarely invited to any parent meetings or assemblies in schools. One parent stated:

> *I haven't met anyone here. … If we [parents and teachers] could meet and talk to each other, we could give advice and have a mutual consultation. (Parent, Interview 4)*

Other parents had similar experiences. One mother said: 'I have no idea about parent and teacher meetings. This is the first time that I was invited' (Parent, Interview 7). A grandmother shared: 'After my child was enrolled here, there were no such meetings for parents. ... I think, maybe we are not required to come to the school' (Parent, Interview 8). She recalled the time when she visited the teacher:

> *I haven't had any talk with other teachers except the one who teaches these students here in the hostel. … Besides that, when I came here for his enrolment, I went to the office and talked to the head teacher. That's it. (Parent, Interview 8)*

Parents in this research experienced minimal involvement with the schools. Those rare meetings were only to let the parents know about administrative matters or decisions that had nothing to do with the outcomes or the progress of their children. There were no opportunities for the parents to provide advice nor did the school offer any support to them. A mother of a girl with Down syndrome recalled an occasion when she had a meeting with school personnel:

> *I was invited by the school once last year to discuss the allowances that the school is receiving for our children from the government. … However, no meeting was called this year. (Parent, Interview 12)*

Another parent was invited to choose the chairperson of the school management committee:

> *I came once for the parent–teacher assembly. … When someone wishes to run for the chair, s/he would request our vote. Mainly those types of things were done there in the assembly. (Parent, Interview 9)*

As students are with their parents for many years, parents know about their children's likes and dislikes regarding food, sports, study and so on. However, most parents in this research shared that they were never asked about their children's interests. The brother of a girl with visual impairment said:

> *I know, students here want to listen to music and see musical instruments. But the school doesn't ask us about this – what my sister wants to do or what she doesn't want to do. (Parent, Interview 6)*

Some parents did not want to make any comments about their involvement in the school. The father of a girl with hearing impairment, stated: 'When she has any problem, she tells us about it, in her own way. But it's alright' (Parent, Interview 3). However, some parents went on to share that the school did not inquire with the parents even when their children were absent from school for many days. A grandfather of a child with intellectual disability described:

> *Our child hasn't been to the school for many days now; but, you see, the school doesn't inquire about it. They don't ask us, 'why is your child not coming to the school? They don't bother to call us. There is no parent-friendly environment and support for us in this school. (Parent, Interview 11)*

He further compared the situation with his child's previous school in a neighbouring country (where this family was staying for some time for work):

> *If this was the case there, they would promptly inquire. There would be a lot of traffic and sometimes it may take a long time to get to the school. In such cases too, they would immediately call us and ask, 'Why is your child not at school?' (Parent, Interview 11)*

Moreover, the interview and focus group data revealed that parents visit schools only for limited purposes. The brother of a girl with a visual impairment expressed:

> *I need to come to drop her before the school opens and to pick her up before the school holidays. Apart from that, if we like to see her we would come here. In addition, if I happen to come in this direction for other work, I drop in to see her. (Parent, Interview 6)*

That indicates the limited purpose of parents' visits to the school; they 'wouldn't come to the school other than that' (Parents, Interviews 2, 3). Some parents thought that they were not needed 'to do anything', when they came to the school as they were never 'asked to do anything' (Parent, Interview 9). Some parents mentioned that they did not even know the name of their child's teacher (Parents, Interviews 1, 5) and some were on the school premises for the first time for this interview (they may have been to their child's hostel, but the hostel is separate, apart from the school building) (Parents, Interviews 1, 7). A parent stated:

> *I came to that place (points towards hostel with his finger). I saw the sister [aaya] there and left my daughter. I did not go there (pointing towards classroom). (Parent, Interview 3)*

Many parents in this research expressed that the *aaya* was the only person they would meet with at the school. The *aaya* even served as an advisor or consultant for the parents. 'We take advice from the sister [*aaya*], and do not consult with others' (Parent, Interview 4). They discussed with the *aaya* their children's life at the hostel. The mother of a girl with visual impairment admired the *aaya's* amicable behaviour: 'when my daughter becomes sick, the *aaya* would call me and tell me that Sabina is suffering from this or that' (Parent, Interview 7). However, despite the important roles the *aayas* had to play, they are untrained and low-paid staff, suggesting a need for capacity development programs for them.

Parents' stories in this research indicated that schools were indifferent towards developing an environment where parents could feel comfortable to interact with schools. In most cases, lack of two-way communication was reported.

Lack of two-way communication

Parents often expressed that teachers and head teachers did not give due importance to their role. The schools only rarely invited parents for meetings, and parents were not involved in the decision making that affected their children's life at school. Moreover, the parents were not informed of the key decisions made by the school and there was also no opportunity for these parents to meet or interact with other parents.

The lack of two-way communication was evident in several parents' accounts. The grandfather of a child with intellectual disability was concerned that he had never been invited by the school for any meetings or discussions (Parent, Interview 11). The father of a boy with multiple disabilities gave a similar account: 'The teachers did not come forward to discuss with the parents or to take advice from us' (Parent, Interview 17). In the rare cases when parents were invited by the school for meetings, they reported that they did not understand what was said to them. A mother said: 'In the meeting, we were informed that the government stopped releasing funds for lunch. The principal sir told us this. But I did not understand everything' (Parent, Interview 12). The mother of a girl with multiple disabilities shared her experience of a school meeting: 'Teachers would speak, and we would sit in front of them and listen to them' (Parent, Interview 13). The grandmother of a girl with intellectual disability recalled:

> *When we were invited to the school, we did nothing special. They talked about the hygiene, how to keep clean. They provided the uniform to us – shoes, slippers and clothes and food that came from Kathmandu. (Parent, Interview 10)*

In addition, most parents in this research expressed their ignorance about the key decisions made by the school. For example, the hostel of a school was moved from the old location, which was quite a distance from the school, to the *aaya's* house near the school. There was no doubt that this decision was made by the school in good faith; however, no parent was involved in the decision. A mother stated: 'I knew it only later. We are not told anything as to why they moved the hostel here' (Parent, Interview 2). Some parents, while they were visiting their children, even went to the previous location of the hostel: 'I went there first. Then someone told me that the hostel was moved to here' (Parent, Interview 5).

Parents in this research spoke of their experiences of their voices not being heard by the school. They complained that schools were not responsive to their concerns. The grandmother of a girl with multiple disabilities stated:

> *We talked about our problems; but I don't think that they listen to us very carefully ... There was a drunkard teacher. We suggested to the school to change the teacher. Nothing improved. Later, he died because of overconsumption of alcohol. (Parent, Interview 10)*

During the interviews, parents indicated that they were willing to meet other parents undergoing similar circumstances and share their experiences with them. However, many parents shared that they have not met other parents. They thought that a parent-to-parent meeting could be an opportunity for them to share their experiences and knowledge. A mother stated:

> *It is almost one year since my son has been going here; but I don't know how other children's mothers are. They also don't know about me … If we meet each other we can learn many things about our children. (Parent, Interview 1)*

Several parents expressed similar views about meeting other parents. A grandmother stated that schools did not organise any parent-to-parent meetings: 'If I was invited to that, I would have come' (Parent, Interview 8). Similarly, the mother of a girl with visual impairment commented:

> *Our children are living here together for many years. I wish I had the chance to meet them [other parents], but I haven't seen any of them yet. (Parent, Interview 7)*

The father of a boy with hearing impairment stated a similar view: ‘If we could meet and talk to each other, we can share many things’ (Parent, Interview 4). However, some parents recalled moments when they met other parents informally:

> *When I met other parents, I asked, ‘If you have come to know about anything from my sister that is not comfortable for your child, please tell me. I will try my best to fix it.’ (Interview 6)*

Parents in this research saw many benefits of parent-to-parent meetings, including raising a collective voice. The same participant proposed: ‘It would be nice to have discussions among parents. If all of us parents meet and present our voice collectively, that can bring a change’ (Interview 6). Although no parent-to-parent meetings were organised, teachers and school professionals thought these meetings were crucial:

> *Parents will be able to express their difficulties more openly with other parents because they share the same types of problems (sabai ko betha estai ho). (R6, Focus group 1)*
>
> *If a parent teaches other parents, it is very effective. Parent-to-parent meetings could be used for this purpose. (R2, Focus group 1)*

Participants stated that these meetings can help parents feel relieved as they can share their sorrows with others. They could compare their problems with others and try to find a solution (R7, Focus group 2). Another head teacher noted that parents may benefit from the knowledge of other parents, if schools could organise such interaction, because some well-educated people, such as teachers and doctors, who have children with disabilities, can come to the school and teach other parents. They should be asked to come to the school by letting them know that, if they come forward with their support, then the school, children and other parents will benefit (R9, Focus group 2).

Despite the importance school professionals placed on parent-to-parent meetings during focus group discussions, such meetings were not organised in reality. There appears to be a wide gap between what school professionals think and what is happening in practice. Nevertheless, parents’ accounts demonstrated that they were keen to be involved in school activities and school decisions, which is what is presented in the next section.

Parents keen to be involved in schools

Parents in this research showed their eagerness to attend school meetings, be involved in school decisions, talk to the teachers and other staff, and provide whatever support they could. Many parents commented that they would come to the school immediately if they were called to attend any meetings. They could attend schools once or even twice a month (Parents, Interviews 1, 4, 5). They wanted to discuss their child's future in such meetings: 'How is his future going to be, good or bad? If the teacher is free and calls us that would be nice' (Parent, Interview 4).

Not only were these parents concerned about their children's future, they were also ready to provide support if schools seek any:

> *If we are asked for any type of support such as building construction or any other work, we won't say 'no'. If teachers ask us, 'let's do this', we are ready to do that. (Parent, Interview 5)*

Parents in this research were even ready to sacrifice their wages or income if they were asked to attend school meetings. A grandmother of a child with visual impairment stated:

> *If I am asked to come [to the school for a meeting], I think I should come. I should spare a day for his good future. I shouldn't love the money that I can make in a day. (Parent, Interview 8)*

The father of a boy with visual impairment made a similar comment:

> *I will come and discuss with the school people. It is for my child's future. I may lose something today, but I know my involvement here pays back in the future. (Parent, Interview 9)*

These comments were evidence that, despite their financial difficulties, the parents were keen to participate in schools. Parents would come to the school at any cost. The mother of a girl with visual impairment, who had another little baby in her lap during the interview, said: 'If I could not attend, as I have a baby with me; someone from our family will come for sure' (Parent, Interview 7). A grandmother of a child with intellectual disability expressed a similar view:

> *We will attend school meetings. If my husband is not able to make it, I will. And if I am not able to come, our daughter-in-law will be able to attend. (Interview 11)*

Some parents explained that they needed to become involved in the school, because through this they could convey their children's concerns, as students cannot report their concerns to the teachers directly. Teachers can resolve issues only when they learn about them. Such interaction also allows parents to learn from the teachers about their children's challenges and successes (Interview 6).

In contrast to parents' views, some participants in the focus groups did not support these views of parents. A teacher criticised parents:

> *They think, 'We have admitted our children to the school, now teachers will look after our children. It's their responsibility'. … They think, 'When we send them to the school, we have*

> *fulfilled our responsibility. Now, the responsibility rests on the school teachers.' (R6, Focus group 1)*

One of the community members in a focus group was also critical of parents for being demanding and not paying enough attention to their child's studies:

> *they aren't much concerned about children with disabilities. They know they are entitled to 1000 rupees per month; they are more concerned about that money. They don't inquire whether their children are receiving good quality facilities in the hostels, their cleanliness, and other conditions. (R15, Focus group 3)*

In addition, some parents even suggested that schools should set the agenda and time frame for such meetings. For example, one parent had opinion that the school can invite them after the release of exam results so that they can see the results and discuss how well their children were doing at school, as well as providing their comments to the teachers (Parent, Interview 6). For another parent, the agenda for such meetings could be the transition to another school, and students' assignments at home:

> *My daughter is going to study here for two more years from now. Where should I take her after that? I want to sit and talk about this with teachers. … And teachers may ask us to assist our children complete their assignments at home. They can tell us, 'We have given this task to your child for the school holidays. You help them.' (Parent, Interview 3)*

Some parents in this research also indicated their willingness to work with the school and help with their skills and expertise. For example, the mother of a girl with Down syndrome said:

> *I learnt some skills when I was abroad. If the current school had invited me, I would have been able to explain to the other parents how we can help our children with disabilities do different types of activities such as how to comb their hair, take a bath, and play at home. (Parent, Interview 12)*

Another parent, who has expertise in music, also showed his readiness to come to school and teach students music: 'A musician teacher is needed for this school. What I can do is, I can come once a week and teach them music' (Interview 6). From these statements, what is evident is many parents are ready to contribute to school activities. However, parents' potential or the resources parents possess were not utilised by schools properly.

In sum, many parents emphasised that schooling is important for children with disabilities. As in developed societies, school has become a major institution of society and schooling has become an essential part of children’s lives. This stage was related to the second and third sub-questions of this research: What are professionals’ perspectives on parental engagement in the education of their children living with disabilities in this western rural context? What are enabling and restrictive factors associated with parents’ engagement with schools? While some parents did not find a place in a school for their children, those who were able to enrol their children appreciated the schools’ positive role in making a difference in their child’s life and changing people’s perceptions about disability, even if their main desire for their children (academic success) was not met. They were happy for their children as they had achieved some successes from being in the school. Both parents and professionals believed that change in the lives of children with disabilities was possible through schooling.

From the stories of participants in this research, it is obvious that parents’ engagement in schools was limited. The parents visited schools just to drop off and collect their children, or sometimes to see them briefly in school hostels. Parents in this research also indicated that they were not invited by the schools for any consultations or meetings. In addition, they were neither involved in nor informed of the key decisions made by schools. The parents expressed that, while they feel comfortable meeting and talking to *aayas*, they would only rarely meet teachers or other staff at the school. Although both parents and professionals expressed that parental engagement or parent–school partnerships are vital for the success of children with disabilities, it was not evident in practice. Moreover, schools were also indifferent towards the roles parents can play for their children’s positive outcomes. Despite all this, most parents expressed their readiness to participate in school meetings, to meet with other parents and to be involved in the schools’ activities if they are invited to do so.

5.4 Chapter summary

In Section 5.2 I presented the 19 themes that emerged from the parents’ and professionals’ experiences and insights collected in this research. These themes were the results of my deep engagement with the detailed portrayals of four parents and all other interview and focus group transcripts. Prior to obtaining the final set of themes, first I read and reread the four case-focused portrayals and identified a set of initial themes (15 themes were obtained at this time). Second, I analysed the remaining data (the transcripts of 15 interviews and four focus group discussions) with a view to substantiate the initial themes. Finally, I carefully looked for any new themes that could emerge (from which four new themes emerged). Each theme was supported by a number of exemplifying quotations and extracts from the participants, presented in Table 5.1. The themes thus obtained were found to be related to two broad stages of parental journeys: from the birth of their child to diagnosis to seeking a cure (before schooling stage) and the schooling of their children.

In the following section, I expanded on the themes relating to the two main stages of the parental journey. The first stage of the journey includes experiences of parents related to raising their children with disabilities, including seeking a cure, and accepting or adjusting to the child's life – which was a stage of uncertainty. The findings of this stage were presented as a number of themes, namely: a stressful and uncertain start: the birth of a child with a disability, seeking answers, search for a cure, getting a diagnosis, 'We can't afford that', reality check, a pleasant surprise, 'Feeling proud of our children' and the cultural face of gender. The next stage of the parents' journey included the parents' and professionals' experiences and opinions about education and schooling for children with disabilities. This was a stage of disappointment as many parents could not enrol their children in a school, while others found that school did not meet their expectations. The themes that prevailed in this stage included: 'Nothing is more important than education!', inspiring role models, 'I can see a huge difference': the benefits of schooling, a lack of welcome for children, 'They're different from us', poor quality services, parents' expectations of schooling, 'No parent-friendly environment and support for us', lack of two-way communication, and parents keen to be involved in schools.

Further, although both parents and professionals saw that there were benefits from parental engagement in the schooling of their children, this study has revealed that parental engagement in the special needs schools located in a western region of Nepal is limited. However, despite various limitations, the parents were interested in education and desired to make a contribution to the extent of their ability, knowledge, expertise and resources. To a great extent the potential of these parents remained untapped. In the next chapter, these findings are interpreted in the light of existing literature and studies. I conclude this chapter by providing an *in situ* reflection drawing on the data from my research journal, which includes personal thoughts, experiences and feelings about my choice and adoption of methodology and methods for field work and data presentation.

5.5 *In situ* reflection: Reflection on the research process

Before commencing the field work, I had some anxieties such as how to meet participants and start conversations and make them feel comfortable to talk to me. I asked myself, what should I do if I did not reach the required number of participants? Will my participants openly tell their stories about raising and educating their children with disabilities? I wanted to collect the experiences or insights of parents and professionals from three selected schools of a district. I considered seeking help from or *hiring a support person, someone familiar to local people, to assist me to find eligible parents and then invite them to volunteer for the research. The support person might also interview them on my behalf, if so required.*

When I first started my field work, I asked the head teachers of three schools to distribute the recruitment materials to all parents of children with disabilities, and to all other school-related professionals targeted for focus group discussions. Parents were invited to participate in interviews and school professionals in focus group discussions. Subsequently, the parents who showed an interest and participated in the interviews were asked to refer other eligible parents they thought may be interested to participate in an interview. Moreover, to gain the required number of interview participants (initially nine parents), my plan was to identify a few participants through a volunteer/self-selection approach and the rest through a snowball/referral approach. I also thought of visiting neighbouring districts if I could not reach the required number of participants.

To my surprise, many parents contacted me and many even invited me to their homes for the interviews. Although I was initially expecting only nine parents from three schools to respond, I received calls from thirty-five parents expressing their interest in participating in the research. While 10 of these participants came from the self-selection approach, the other 25 knew about my research from other parents, their relatives or friends, through a snowballing approach. However, because of time constraints, I could only manage to talk to 19 parents. Perhaps because of the high prevalence of disability cases in the region, a large number of participants showed an interest in participating in the research. As I had a sufficient number of participants, I did not have to go to neighbouring districts to reach out to further participants. I believe the snowballing sampling approach I used worked extremely well and hence the impression I gained from this experience is that rural and remote settings such as this research area can provide a rich source of important participants through a snowball sampling approach. In addition, in my view, this sampling approach, being interwoven with participants' relationships with each other, fits easily with relational-centred research.

Additionally, people in rural remote areas of Nepal were friendly, approachable, welcoming and supportive. Many parents invited me for dinner in their home; some offered me tea and snacks. They treated me as their guest, affording me honour and respect according to Nepalese culture and customs. In Nepal, the cultural notion of hospitality is guided by the Hindu doctrine that says 'atithi devo bhava' (that is 'a guest is like a god'), which reveals an ideal relationship between host and guest in Hinduism, as mentioned in the ancient Sanskrit script Taittiriya Upanishad (Clooney, 2011;

Duwadi, 2013; Kearney & Taylor, 2011; Tyagananda, 2011). I found this ideal reflected in the attitudes and behaviour of all my participants.

Another feeling I had from the field is that, when people were interested in talking to me, it was hard to refuse their invitations. It is particularly difficult for a researcher if he/she is from a culture like mine, where people cannot say 'no'. Even though some parents did not meet my inclusion criteria, I interviewed them. For example, I talked to the father of a man with visual disability who was 30 years old and well above school age (Participant 15, Table 3.1). However, it was worth spending time with him because I received interesting and meaningful stories that were related to my research. Nevertheless, I could not talk to all parents who showed an interest in this research. Moreover, I felt that all participants to whom I talked were delighted to share their stories with me. With this experience, I felt, to work with people at the local level we need to choose methods that are grounded in their everyday lives and that do not create inconvenience for them. For this, interviews in the form of informal conversations and interactive vignette-based focus group discussions used in this research served as best fits. Informal interview conversations invited stories (Ban, 2015) and allowed me to access the lives of participants who had been 'hidden, made inaccessible, suppressed, distorted, misunderstood, ignored' (DuBois, as cited in Liamputtong, 2007, p. 1).

The challenge of this research was to gain access to locally situated people without disturbing their daily schedules and chores, and to communicate with them about sensitive issues in their lives without hurting them. I had great respect for these people from my heart from very start of the research, but I had to prove it by my actions during the field work. In this respect, seminal works by Finlay and Evans (2009) such as 'Relational-centred research for psychotherapists' and from Liamputtong (2007) such as 'Researching the vulnerable' were particularly useful for me. These works provided insights into how to respect participants' dignity and sensitivities during different phases of the research. For Liamputtong, researching vulnerable groups of people is different from researching other groups of people and therefore 'extreme sensitivity is needed in the conduct of research' (p. 6). Through Finlay and Evans' relational-centred inquiry, I learned how to respect participants and value their feelings, thoughts, sentiments and opinions. During the conversations and focus group discussions, I was willing to rely on my participants' (parents' and professionals') ideas. To me, my participants were not only respondents to my queries; rather I also encouraged them to ask questions. I wanted to be asked whenever they had doubts. The relationship I was willing to have with my participants was based on equality and reciprocity, or a dialogical one. My reliance on relational-centred research proved to be the right choice to achieve this. Relational research guided me to enter into their life spaces, which assisted me to understand their experiences and *contexts, which were new and unfamiliar to me. I also tried to put myself in their place and tried to see the world through their eyes. I may not have felt their experiences in the same way as they experienced them. However, I felt the content of their stories and how openly and frankly they shared those stories with me. Insights obtained from the literature were incorporated in the different stages of research such as while sampling, accessing participants, eliciting data from them, analysing and presenting the data.*

Moreover, presentation and analysis of two types of data obtained from informal interview conversations and focus group discussions was a big challenge. However, by employing case-focused and thematic narrative techniques, I was able to analyse and present the selected stories of parent participants in the form of detailed portrayals (Chapter 4) and the rest of the data in the form of thematic narratives in this chapter (Chapter 5).

Overwhelmingly, the message I received from my field work is that Nepal has a profound storytelling culture. My participants let me into their lives through relational research supported by storytelling methods. Many people eagerly contacted me to participate. Many participants were able to tell their stories for the first time to someone like me, an outsider. This can be linked to the notion that people want to tell their stories to relieve their stress. Possibly people were in search of opportunities to discharge some of their stress by venting their experiences of being with (or living with) their children with disabilities. Therefore, it can be concluded that a narrative approach underpinned by relational research is an appropriate choice to work with the hard-to-reach and marginalised people residing in rural areas of Nepal, as also evidenced in the interview data:

> *It would be better if people come to us from time to time to learn about our situation and our difficulties. We are happy to tell what we know. We don't have any forum to articulate our problems. To whom would we talk about our problems? We would just keep them within ourselves. If we have space to spill our sorrows that makes us relieved; we become light. Then we feel like, 'Oh! I got this opportunity to express my problems and opinions to others.' We can also become more hopeful. We can expect something new for the future. It has already been two years since my daughter has been enrolled in this school; no one has talked to me like this before. (Parent, Interview 7)*

Moreover, the share of female participants was remarkable in the parents' group; 10 of 19 parents were female. However, in the focus groups, there were only three female participants of the total 23, indicating the skewed representation of women in professional positions. Being a male researcher, initially I was unsure about how frank and open the women would be with me given the cultural context of Nepal. It is uncommon for males and females to interact, particularly in rural areas.

However, the female participants made me welcome, for example, inviting me for tea, and provided very detailed information. They were so supportive that I was able to elicit rich and detailed experiences and insights in the form of stories. Thus, I collected comprehensive information from both female and male participants and my perception was that their contribution to this research was very real.

In addition, I also collected some unique experiences while conversing with the participants. For example, some participants would receive phone calls and would explain to the person at the other end that they were sitting in an interview with me. In some cases, other family members also joined and contributed to the conversations initially planned to be held between a parent and me. This happened on four occasions, especially in the interviews undertaken at participants' homes (Table 3.1, interview participants 10, 11, 15 and 17). In Nepali culture, as also is the case in India as described by Bhati (1979), 'usually it is not possible to interview … in privacy. Members of family, friends and neighbours of a respondent are generally around at the time of interview' (p. 79). Moreover, if a participant sits with the researcher alone and talks for a long time, people may view them with suspicious eyes and may become curious to know the matters they are discussing. Sudden interference or the uninvited presence of a stranger in the conversation between two people is quite normal. I found this in line with Riessman's (2008) observation that a society guided by collective cultural practices allows people to come and go during the conversation between two people. Unlike in the western context, it is not considered impolite and a culturally unsuitable practice in Nepal.

Similarly, in the focus group discussions, the participants initially talked about contemporary issues, such as the local election. This is also a normal practice in Nepal. When people meet, they greet each other, ask about their health and families, and talk about contemporary issues before starting the meeting – this act in other cultures may be termed 'beating around the bush'. Moreover, not all participants arrive at the stipulated time and it is quite common to wait for a while for those participants to come and only then commence the meeting. During the waiting time people discuss different practical and other issues not related to the agenda of the meeting, so in our case, they discussed the upcoming election. In the next chapter, I interpret the findings of this research in the form of the key finding and consolidated findings arising from the portrayals and thematic narratives presented so far.

CHAPTER 6 - INTERPRETING THE FINDINGS: DISTILLING THE MEANINGS OF PARENTAL EXPERIENCES IN THE LIGHT OF RELEVANT LITERATURE

> Of the all pursuits open to men [sic], the search for wisdom is more perfect, more sublime, more profitable, and more full of joy. (Thomas Aquinas, ~ 1260)[23]

6.1 Chapter introduction

This chapter presents a central finding and a set of consolidated findings derived from the themes elaborated in Chapter 5. Interpretations in this chapter respond to the research questions relating to parents' and education professionals' experiences of and perspectives on the care for and schooling of children with disabilities in the light of relevant research from developing and developed countries.

6.2 Central and consolidated findings

This research's key finding is that parents of children with disabilities in the region in Nepal selected for this research are as yet an untapped resource in that they are willing to work in partnership with schools but face significant obstacles that limit their opportunities to do so. Even though the parents who participated in this research are clearly invested in their children's wellbeing and education and are willing to become more engaged in school activities, education professionals including teachers find it very difficult to see how they could have anything to offer. This research, however, has found that parents of children with disabilities have much to offer in terms of wisdom, skills and local resources but they face significant barriers, as they:

- make sense of the causes, cures and implications of their children's disability and what this means for their children's education and their lives;
- try to access services such as health and education for their children, but they experience significant suffering due to the lack of external support;
- cope with the dominant patriarchal culture in their communities, which in turn has placed further stress particularly on families of girls with disabilities as well as the female members of those families;
- spend the early years of their children's lives consumed with navigating healthcare needs before they even get to education;
- try to come to terms with the realisation that education does not seem to be easily available for children with disabilities, although they highly value it and are invested in it; and

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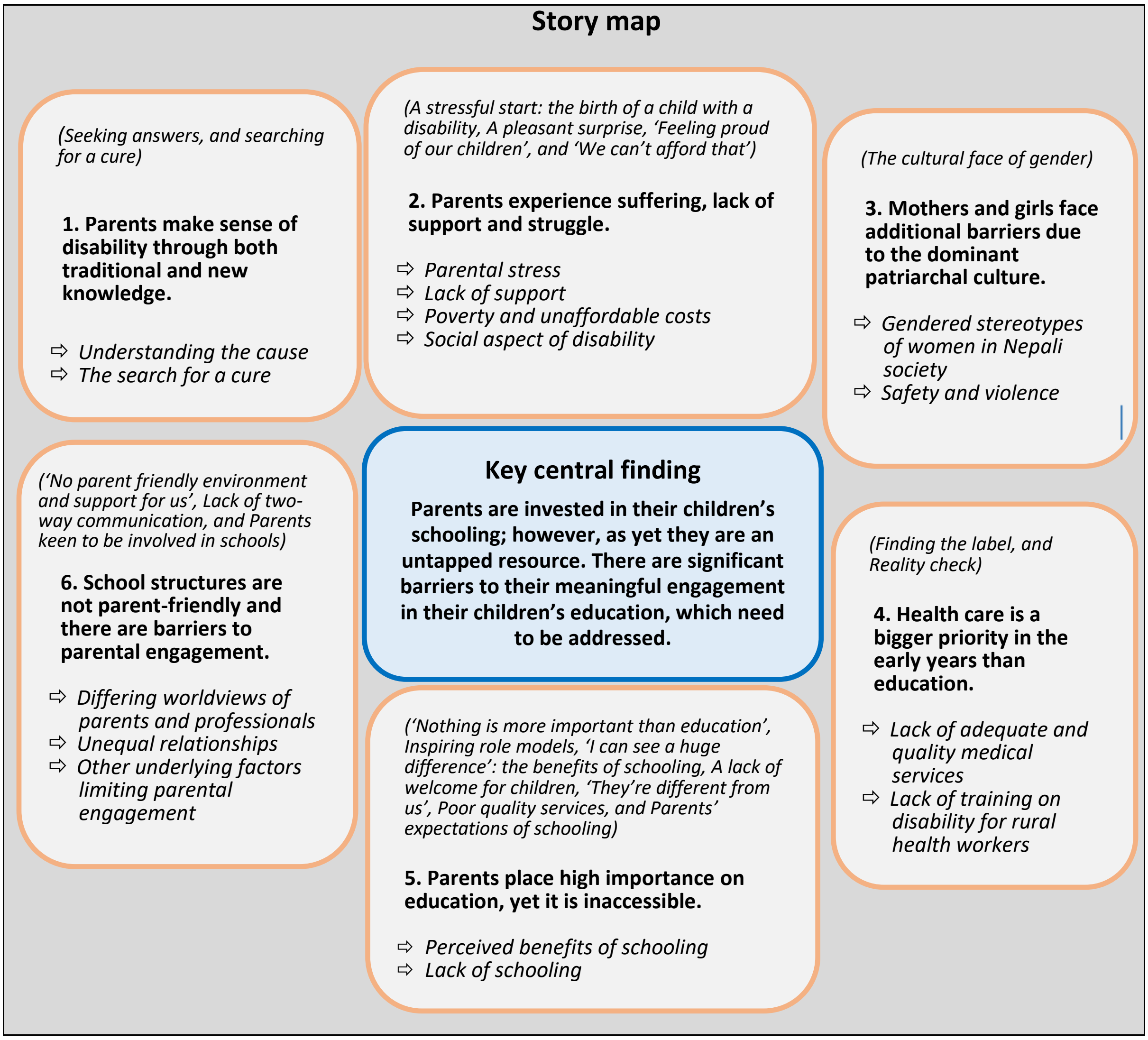
[23] Thomas Aquinas Quotes. *A–Z Quotes*. Retrieved on 29 March 2019, https://www.azquotes.com/author/490-thomas_aquinas

- feel unwelcome and unappreciated in schools due to professionals’ perceived indifference towards their willingness to contribute to their children’s education.

The six types of experiences of the participants, as stated above, formed the consolidated findings of the research, which are:

- Parents make sense of disability through both traditional and new knowledge.
- Parents experience suffering, lack of support and struggle.
- Mothers and girls face more barriers due to the dominant patriarchal culture.
- Health care is a bigger priority than education in the early years.
- Parents place high importance on education, yet many children with disabilities do not benefit.
- School structures are not parent friendly and there are barriers to parental engagement.

Aligning with the narrative approach employed for data presentation and analysis, the overarching central finding and consolidated findings are depicted in a story map (Figure 6.1). As mentioned in Chapter 3, presenting the findings in the form of story map is a useful tool in research to facilitate the inquiry process and enhance understanding, as it ‘provide[s] a holistic account of the phenomenon under study and assist[s] researchers to make meaning of nuances within complex narratives’ (Lapum et al., 2015, p. 1).



Story map

(Seeking answers, and searching for a cure)

1. Parents make sense of disability through both traditional and new knowledge.

- *Understanding the cause*
- *The search for a cure*

(A stressful start: the birth of a child with a disability, A pleasant surprise, 'Feeling proud of our children', and 'We can't afford that')

2. Parents experience suffering, lack of support and struggle.

- *Parental stress*
- *Lack of support*
- *Poverty and unaffordable costs*
- *Social aspect of disability*

(The cultural face of gender)

3. Mothers and girls face additional barriers due to the dominant patriarchal culture.

- *Gendered stereotypes of women in Nepali society*
- *Safety and violence*

('No parent friendly environment and support for us', Lack of two-way communication, and Parents keen to be involved in schools)

6. School structures are not parent-friendly and there are barriers to parental engagement.

- *Differing worldviews of parents and professionals*
- *Unequal relationships*
- *Other underlying factors limiting parental engagement*

Key central finding

Parents are invested in their children's schooling; however, as yet they are an untapped resource. There are significant barriers to their meaningful engagement in their children's education, which need to be addressed.

(Finding the label, and Reality check)

4. Health care is a bigger priority in the early years than education.

- *Lack of adequate and quality medical services*
- *Lack of training on disability for rural health workers*

('Nothing is more important than education', Inspiring role models, 'I can see a huge difference': the benefits of schooling, A lack of welcome for children, 'They're different from us', Poor quality services, and Parents' expectations of schooling)

5. Parents place high importance on education, yet it is inaccessible.

- *Perceived benefits of schooling*
- *Lack of schooling*

Figure 6.1: Story map depicting parents' journey

In the story map, the placing of the key central finding at the centre and the consolidated findings around the central finding indicates the connected nature of the consolidated findings, both to the central finding and to each other. Additionally, each consolidated finding is backed up by the supporting themes (shown in parentheses in the map) of Chapter 5, to demonstrate how the consolidated findings have emerged from the themes previously discussed, as well as to maintain the close connection to the data. Each consolidated finding is further explored in turn in the following sections under several sub-headings that are also reflected in the story map.

6.2.1 Parents make sense of disability through both traditional and new knowledge

While most of the parents in this study uphold religious worldviews about the causes of disability, at the same time, they also have faith in modern medicine. Their belief in traditional religious causes concurs with Paudel, Javanparast, Dasvarma and Newman's (2018b) recent study undertaken in a remote mountain district in Nepal, which found that mothers and families in rural areas tend to attribute their children's sickness to God's displeasure, fate or destiny. This also confirms earlier findings that approximately one-third of Nepali people believe in a metaphysical cause of disability (UNICEF et al., 2001). Interestingly, in this research scientific knowledge encountered by parent participants can be viewed as only an 'add-on' to their existing knowledge base. New knowledge the parents within this research encountered has not necessarily replaced their reliance on traditional systems. Recent interventions, such as healthcare services, have rather provided some more choices and options for them to consider, so that they can see doctors along with traditional healers. It appears that, at times, armed with their new knowledge, parents experienced confusion and frustration, as explained in Chapter 5, that their hopes to find a cure for their child had eroded after visiting doctors and hospitals.

Understanding the cause

Parents in this study saw the cause of their child's disability through a religious lens, as faith continues to be a very important aspect of people's lives in Nepal. This aligns with research conducted in other South Asian countries, where 'parents tend to attribute their child's disability to God's will or personal failure' (John, Bailey, & Jones, 2017, p. 671). In Nepal, religious beliefs and views are deeply underpinned by the doctrine of *karma*, possibly due to Hinduism and Buddhism being the dominant religions of the country, which attributes disability to one's *karma* (result of one's actions). It explains that inappropriate actions performed in a previous life/lives or even in this life can result in unpleasant consequences in the present life such as illness or disability (Shree, 2013). More precisely, it is believed that any inappropriate action or anything that does not align with the *dharma* (duties that are expected in accordance with the law of nature) can result in undesired outcomes (Radhakrishanan, 2002; Paudel et al., 2018b; Sarvapriyananda, 2018; Shree, 2013).

Interestingly, the present research revealed that the parents longed for medical treatment, although it was often not readily accessible to them due to limited financial means and long geographic distances to reach health facilities. Parental engagement with these modern practices in this research can be attributed to their quest to improve their children's conditions such as their wellbeing and education, and this growing awareness can be attributable to the current growth in the number of health facilities, schools, communication and information systems, and the commercialisation of medical services in Nepal. A similar trend is observed in Bhutan as the introduction of modern social institutions such as schooling and health care have been found to bring new understandings of disability, according to Schuelka (2015). This clearly suggests that the medical/scientific view is in competition with the cultural/religious view of disability in Nepal. This again exemplifies that in Nepal, with the growing exposure to modernity, while medical beliefs are in competition with religious beliefs in more urbanised environments, in the more rural areas, the traditional beliefs continue to be a dominant influence on people's perceptions of and the way they deal with disability.

When parents in this research received advice and information from medical experts, they often became more confused, because they could not see any relationship between their traditional folk knowledge and the newer scientific knowledge. It was difficult for them to make sense of these different pathways, as their conceptualisations of and approaches to treatment for their children's disability were often in conflict. Despite this, they sought guidance as well and they were open to new information, continuously displaying their active agency and refusing to give up.

The search for a cure

As found in the data, most of the parents tried traditional faith-based healing systems such as *dhami* (faith healers), *jhankri* (shamanistic treatments) and *jyotishi* (palmistry). This supports the recent work undertaken in a western mountainous district of Nepal by Paudel et al. (2018b) who found families seeking cures via *dhami, jhankri*, priests, astrologers, palmists and animal sacrifices, as they continued to believe in traditional knowledge. However, my finding contradicts the findings of a study by Raut and Khanal (2011) from the eastern part of Nepal, which concluded that traditional healing is 'declining and in many cases, facing extinction' (p. 879). According to Morrison et al. (2008), Nepali parents from rural areas seek a traditional cure first and when they do not find a solution from the traditional approach then they seek modern health services, which includes all modern medicines, technologies and practices available. Even though seeking traditional faith healers was the first priority, if this did not yield positive results parents sought medical advice.

There may be a conflict between parents' beliefs regarding the causes of disability and their cure-seeking behaviour; however they are not concerned about this. A qualitative study from Nicaragua (Matt, 2014) seems to concur with this interpretation, reporting that 'beliefs regarding the cause of disability do not influence parents' health care seeking behaviours for their children' (p. 13). The openness of the parents in this research to seeking a cure from both traditional and modern ways indicates that their desire to help and care for their child takes precedence over the adoption of either approach. In this sense, each approach was viewed pragmatically for what it could offer them. In the West also, there is increasing interest in traditional medicine. Ayurveda, for example, is increasingly being used to understand and manage diseases in the modern world (Morandi, Tosto, Sartori, & Roberti di Sarsina, 2011).

The relational approach taken to this study reflects a balanced view that can incorporate different perspectives – both traditional and scientific (Finlay & Evans, 2009). This line of thought corresponds to a recent initiation of medical pluralism (Oliver, 2013), which integrates the biomedical or modern healthcare system with traditional medical practices and sees the possibility of practising both concurrently. Moreover, the recent initiative of the South Australian Government to include Aboriginal faith healers along with the modern healthcare system is further evidence of this growing recognition of folk wisdom. In this initiative, 60,000-year-old medicinal practices that comprise touch, breath and bush medicines are used alongside modern medicines (Burnie, 2019; see also Condie, 2019). Traditional ways of understanding disability and seeking cures as shown in this study, therefore, continue to have relevance and are valued so they should not be simply abandoned. The coexistence of these different ways of thinking indicates that both ways need to be acknowledged by health and education professionals who have early contact with families. The implications of this finding are further elaborated in the next chapter.

6.2.2 Parents experience suffering, lack of support and struggle

This research has revealed that the parents of children with disabilities who were interviewed underwent varying levels of grief throughout their journey of childrearing, searching for a cure and connecting with their children's schooling. However, their active efforts and their struggles to cope with adverse situations, despite the lack of external support, were not generally admired and acknowledged. This finding is interpreted under four sub-headings, namely: parental stress; the lack of support systems; poverty and unaffordable costs; and lack of awareness about the social aspects of disability that exacerbate their already adverse situations.

Parental stress

Parents in this research reported a repeated cycle of grief comprising stages of uncertainty (both despair and hope together), acceptance, celebration and reoccurring despair. As described in the literature review, various studies have found that it is not uncommon in adverse situations for people to undergo stages of emotional stress that could take the form of disbelief, guilt, rejection, anger, denial and a feeling of helplessness (Sajjad, 2011; Kübler-Ross, 1969/2003; Corr, 1993; Boushey, 2001; Ferguson, 2002).

In this research, parents displayed varying levels of stress at different stages of their journeys. As suggested by participants' stories, the level of stress varied due to a number of factors, such as the worldviews upon which they constructed the meaning of disability, the severity of the disability in question and the availability of support from family members, relatives or beyond. This research supports studies from India (Gupta & Kaur, 2010; Upadhyaya & Havalappanavar, 2008) and Pakistan

(Azeem et al., 2013) that found that the level of stress of parents is associated with the severity of their children's disabilities, age and behavioural issues of the child, and supports and services available to them. In the context of poverty and a lack of support structures it appears undeniable that parents go through a repeated cycle of stress and grief. Moreover, the grief of parents living with children with disabilities is much more ongoing than the grief caused by loss or death.

There are different explanations for why the grief experiences of parents of children with disabilities differ from the grief experiences caused by loss or death. While stresses reoccur only rarely in the case of grief associated with death, or fatal diseases leading to death (Furnes & Dysvik, 2010; Harris, 2011; Harris & Gorman, 2011; Kurtzer-White & Luterman, 2003), in the case of parents living with their children with disabilities stresses occur repeatedly. Kurtzer-White and Luterman (2003) differentiate grief caused by death and disability: 'Death grief is terminable whereas parental grief [caused by disability] is chronic' (p. 232). Similarly, Seligman and Darling (2007) from the United States have highlighted the different types and intensities of grief parents and families undergo due to a life loss and when they have a child with a disability in the family. In the disability case, the authors stated that it depends on 'the nature and severity of the disability, and the types of support and assistance that are available' (Seligman & Darling, 2007, p. 186). However, the cases should be generalised only very cautiously across parents and families, as the needs and context of every parent/family are different (Seligman & Darling, 2007). For example, Paudel (2018) found in his research on neo-natal care in the western mountainous district of Nepal that parents generally accept the death of a baby by attributing it to *karma*. However, while parents living with their children with disabilities in my research were helped by their belief in *karma*, they continued to face additional and ongoing pressure to meet the care needs of their children.

Stress has a wide-ranging impact on families and communities. For example, in this research stress greatly impacted the quality of parents' life, the general health and wellbeing of all family members, and their day-to-day chores. Normal daily life was paralysed, which in some cases manifested in the form of chronic grief and depression in mothers and fathers. Parents' experience of chronic grief in this research corroborates Seligman and Darling's (2007) observation that 'chronic sorrow is a normal reaction to parenting a child with a disability' (p. 190). In some cases, families' experiences are extremely painful, as Seligman and Darling (2007) noted: 'a family may see only despair, dependence, and social isolation' (p. 191). However, this does not mean that parents give up, as they love and care for their children: 'a parent who continues to experience sadness about a child's disability can still be a competent and caring parent' (p. 190). This tendency was clearly visible in this research also; despite experiencing chronic grief, parents were active and coped with struggles, as expressed by a parent: ‘We should not accept defeat, we should seek ways to proceed’ (Parent, Interview 14).

Many parents in this study feared disclosing their child’s disability to the wider community. Concealing disability in Nepal is associated with social stigma and verbal abuse of persons with disabilities and their family members (Barriga, 2011). This finding concurs with other studies, including those from Africa and Nepal. Otieno (2009) in the Kenyan context notes that ‘disability stigmatizes not only the individual but the whole family’ which contributes to the exclusion of persons with disabilities from ‘the social, economic, political, and spiritual spheres of society’ (p. 4). Due to the ‘shame associated with disability’ many Kenyan parents do not send their children to school (p. 18). Otieno describes that parents’ strong belief in religious causes and their tendency to attribute their sons’ and daughters’ disabilities to their own sins, have led them to hide disability to avoid the social stigma. In Nepal, Shah Thapa (2012) observes that some parents hide their child’s disability because they feel ashamed and humiliated. Moreover, Barriga (2011) observes that such feelings prevent some Nepali parents from registering their child in census data or even for identity cards. However, parents’ accounts in this research did not support the findings from Barriga’s study, as the parents tried to access disability cards from government offices and were more open to discuss the disability of their child as long as they saw any potential of receiving support for their children. This may be due to the trend that concealing a child’s disability has been waning in recent years in South Asia. For example, in India, it has been noted that there is a ‘growing visibility of disability in education and broader official discourses and popular media’, as observed by Singal (2016a, p. 37), and it is similar in Nepal according to Shah Thapa (2012).

Nevertheless, parents in this research also experience moments of joy, pleasure and rewarding experiences. As discussed in the literature review (Gupta & Singhal, 2004; Lodewyks, 2009, 2015), and found in this research too, religious-spiritual beliefs and practices may have helped parents develop such positive feelings and resiliency, accept disability at the earliest possible stage, and celebrate the achievements made by their child with disability. According to Paudel et al. (2018b) it is quite common in Nepal that religious beliefs enable people to accept and emerge from tragic life events and become resilient in coping with adverse situations. Similarly, another explanation for the development of such resilience in parents could be that with the increasing opportunities for parents in this research to expose themselves and their child to people outside their homes, they could compare their own lives with those of other families and parents living in similar situations and may have felt relieved. However, external supports for these parents were extremely limited.

Lack of support

Parents in this study experienced intensified challenges when they did not find any external support related to early intervention or diagnosis, treatment and rehabilitation, health care, financial help and education. Studies by Mackay (2003) from New Zealand and Sajjad (2011) from Pakistan also support the idea that the availability of early intervention and social or psychological support helps parents and families develop resilience and cope with disability issues and manage the subsequent stresses. While proper and timely diagnosis could provide relief and help lessen parental distress, the significant delay in diagnosis reported in this research may have added an extra level of grief. Lack of early diagnosis and treatment facilities for disability have also been reported in previous studies in Nepal (Shah Thapa, 2012) and India (Muthuvel et al., 2017), and occasionally in developed countries too, for example in the case of ‘autism’ in Australia (Gill & Liamputtong, 2013, p. 52). Shah Thapa (2012) and other studies in developing countries have found that parents often feel relieved when they get a diagnosis because at least they understand why their child was not developing as expected (Rogers, 2007). For Hsiao (2013), as well as in this study, parents’ struggles to obtain a diagnosis negatively impacted their own health and wellbeing.

Moreover, proper rehabilitation systems could have provided some relief for poor parents in rural areas. However, such services in Nepal are not adequate; only a limited number of rehabilitation centres are available and they are located in a few big cities. Although Nepal was one of the first countries to implement community-based rehabilitation (CBR) programs as early as 1985 (Kafle, 2010; Mendis & Gurung, 2007; Mol, Van Brakel, & Schreurs, 2014), no substantial effect of such programs is evident in rural areas such as where this research was undertaken. Some studies report mixed findings about the success of rehabilitation programs in Nepal (Kafle, 2010; Prajapati, Khatiwada, Prasain, & Maharjan, 2015); however these studies have the methodological limitation that they assessed the impact of the programs only on the population which received the intervention, without comparing the impact with a control population. By and large, this indicates that the CBR program has barely achieved its aim ‘of improving the situation of children with disabilities through the fulfilment of child rights’ (Kafle, 2010, p. 2). An earlier study from Nepal also notes the similar low impact as ‘Less than 2–3% of people with disabilities have received any kind of rehabilitation services’ (Dhungana, 2006). In contrast, India has some success stories of CBR programs in terms of their geographical expansion (Nagarajan, 1998, p. 53); as well as in terms of enhancing the wellbeing of persons with disabilities, ‘fighting stigma, [and] promoting empowerment’ (Biggeri et al., 2014, p. 1515). This research envisions a need for rehabilitation services for at least children with profound disabilities, which is further discussed in the next chapter.

Due to the lack of such basic services (early diagnosis, intervention and rehabilitation), parents have to leave their child at home when they go to work, which has severely impacted the quality of life of children and their parents. A previous study, undertaken in the far west of Nepal, reports a similar case to a participant in this study in which: 'some parents … had no choice but to lock their children in a room or tie them to a post while they went to work' (Barriga, 2011, p. 77). One of the reasons for the lack of services may be that in Nepal there has been a culture of older family members taking responsibility for caring for children in general; in essence this cultural practice may be why there have not been more effective care services put into place, particularly in rural areas. However, this practice may fall short of the care needs of children with disabilities, which are different and demanding. In addition, these cultural practices (older members of families taking care for young children) seem to be currently eroding due to the move towards the nuclear family structure in Nepal.

Lack of understanding and sensitivity on the part of government and civil society is also evident in Nepal. Government services available from *gaunpalikas* (village councils, the lowest level of government to deliver public services) and district headquarter offices are not enough. In addition, both local and international NGOs are present and play a crucial role in the advocacy aspects of social issues in developing countries like Nepal (Mendis & Gurung, 2007), but they have not reached the rural and remote parts of the country. In remote Nepal, people with disabilities are often the last in line to receive support, although policies frequently claim that their priority is to help the vulnerable and marginalised first. Amidst the poverty and lack of resources of local governments, families with disability often remain at the bottom of the local government's priorities. For example, parents in this research often expressed that *gaunpalika* are not prompt in delivering services and not supportive of people with disabilities. Moreover, *afno-manchhe sanskriti* (own-people culture) (Bista, 1991) is clearly visible while receiving services, as evidenced in a parent's quotation:

> *When I went to the council with my nanda [husband's sister or sister-in-law, who knew the gaunpalika's staff], they did our work so fast that I could not believe. An officer searched our paper, did all the work so quick, and they gave me the allowances of three months. … I have never imagined such work from the council's people. I was with my nanda, and that actually did work. (Parent, Interview 7)*

An *afno-manchhe* is a culture of favouritism based on personal relationship, that is, if one knows the people in the office one can obtain prompt services; otherwise, nobody listens. In this context, this research identifies a need for awareness and empowerment programs (elaborated in the next chapter) for frontline service providers so that they can honour and respect everybody equally including parents of children with disabilities.

Poverty and unaffordable costs

This study found that the presence in a family of a child or adult with a disability heavily impacts the family's financial condition, even more so for rural or remote contexts given the limited support, poverty, and associated costs of care, treatment and medicines. Parents in Nepali society generally expect that their child will be their primary support person (financially and emotionally) during their old age; however, this is often not possible for parents of children with disabilities. In a society like Nepal, if a child with a disability is born, parents are the ones who have to face the most hurdles; the situation is compounded by the lack of social services and support from outside. These findings align with a study from Uttar Pradesh (a state of India, which shares a border with Nepal) that reports 'stories of families selling land, businesses etc.' to support costs associated with a disability (Varghese, Grills, & Matthias, 2015, p. 65). Social security entitlements and benefits could have assisted parents living in such misery; however, the current level of social security benefits in Nepal that persons with disabilities are entitled to, known as the 'disability allowance', is inadequate and sometimes does not reach the target group (Barriga, 2011). Eide, Neupane and Hem (2016) are critical of this government provision, as they note that 'this is a "power" rather than a "duty"', because such benefits are subject to resource availability (p. 31). This means that the disability entitlement has not yet been guaranteed. The disability allowance in Nepal is granted on the basis of the severity of the disability and managed through four types of colour-coded cards.[24] This research found that, although the disability allowance is not adequate, through disability allowances, people feel connected to the government. Having their names in the government register alone means a lot to rural people; they feel ownership in the functioning of the government.

While in advanced societies there are several support provisions, such as insurance, community health, employment and social welfare, to assist families, such supports are rarely present in Nepal, even more so for the remote and rural villages of Nepal. Australia, for example, has a scheme called the National Disability Insurance Scheme 'that provides insurance cover for all Australians in the event of significant disability' (Productivity Commission, 2011, p. 2). Funding for the scheme is guaranteed as it is considered a core function of government. The current debate in the West centres on the quality and sustainability of these support provisions, rather than the entitlement. It could also be that most of the services rely on extra money provided by taxpayers to the

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[24] Red for profoundly affected, blue for severely affected, yellow for moderately affected and white for persons with mild or ordinary disabilities.

government to support the scheme. Paying additional tax in Nepal is unlikely to be popular as income is limited and hence the government must rely on international support. Linking back to the literature reviewed in Chapter 2, developing countries like Nepal continue to fight just for the availability of services, irrespective of whether the services are segregated or integrated with the mainstream. Meanwhile the developed world is concerned with the true inclusion of such services with a full understanding of inclusiveness, embedded in values of human rights, equality and zero tolerance towards discrimination at all levels from government policy to everyday interpersonal interactions. To move towards a more inclusive approach to supporting the needs of families of children living with disabilities, Nepal needs to expand its existing services to cover all people with disabilities and initiate new schemes such as health insurance for people with disabilities and their families. Clearly this would be a complex policy initiative which may take much time and strong government and community commitment.

Social aspect of disability

This research demonstrates that parents and professionals have experienced many social barriers created by social structures, infrastructure, limited finances, attitudes and cultural norms. Social aspects can be both tangible, such as roads, buildings, ramps and transportation, or intangible, such as beliefs, attitudes and expressions. Social aspects of disability are part of the wider socioeconomic environment that impacts living standards for all including those with disability. This study has found that parents and professionals in this research lack an understanding of the social aspects of disability such as the rights of persons with disabilities. This may have prevented parents from pursuing their children's rights to access support services and insisting that professionals design and offer appropriate services.

As mentioned in the literature review, the social perspective of disability is based on the rights-based and empowerment approaches (Regmi, 2017). Lack of understanding about the social elements of disability in the participants of this research may be due to the hierarchical nature of Nepali societies where relatively well-off people, who hold power and are in charge of the delivery of services, are reluctant to talk about issues related to the rights and empowerment of persons with disabilities and their families, as it would challenge the status quo. This lack of understanding might also be due to the lack of awareness programs about rights and empowerment particularly for people in rural settings. While they may not be able to verbally express social aspects of disability, these barriers seem obvious in the lives of children with disabilities, and their parents and families. Policy makers, professionals and members of the community need to recognise these social factors as influential in the exclusion of persons with disabilities and contemplate ways to eliminate the negative effects of such barriers in the lives of persons with disabilities and their families. In the next section, I discuss the effect of the patriarchal culture of Nepali society on the female members of the families studied.

6.2.3 Mothers and girls face more barriers due to the dominant patriarchal culture

The stories of the participants in this research suggest that the female members of the family suffer more than their male counterparts. Women's suffering is manifested in two ways: firstly, compared to fathers, mothers of girls with disabilities bear more responsibilities in raising their children; and secondly, the disability of a girl child adds extra grief and stress for the parents. Such discrimination is attributable to gendered stereotypes caused by the patriarchal culture that places different responsibilities and expectations on a girl child and a woman in a family. The sections below examine the complex intermixing of disability and gender operating within the life experiences of girls with disabilities and female members of families with a child with a disability.

Gendered stereotypes of women in Nepali society

Traditionally, Nepal, due to complex intersecting cultural, social and religious beliefs, has prevented females from fully contributing to decision making in both familial and societal matters, which has resulted in girls and women not receiving their reasonable share of different facilities, including education, health services and participation in social activities (Shah Thapa, 2012). The findings of this research on the suffering of women and girls resonate with similar research from the region, such as studies from India (Alur, 2007; Mukhopadhyay, 2009) and Pakistan (Hammad & Singal, 2014). Therefore, women in Nepal are in a lowly position, often with little voice and confined within household premises. The dominant patriarchal culture has left females with a weaker voice in decision making (Paudel, Javanparast, Dasvarma, & Newman, 2018a). Females are, in most cases, engaged in the nurturing responsibilities for their children, and their work is not counted as productive. A similar division of roles between male and female family members is reported in Pakistani society (Azeem et al., 2013; Hammad & Singal, 2014; Mir, 2008).

In addition, the dominant socio-cultural values and beliefs in Nepal result in further alienation of girls and women with disabilities, even making them invisible in many ways, such as in the census reports (Barriga, 2011). Moreover, they suffer more due to poverty, their lack of rights to inherit paternal property, inability to compete for scarce family/public resources, domestic violence, limited access to education and employment, and lack of external support even in the case of reported abuse.

In such circumstances, as evident in this research, women with a child with a disability become more vulnerable. Firstly, their burden of responsibility for the household and the children with a disability is perpetuated because household responsibilities including taking care of children are considered women's only tasks. Secondly, when the child with a disability is a girl, it is the mother who has to suffer the most both inside her family and in communities. Although men and other family members also suffer, stigma and discriminatory behaviours are targeted more at women in general. This research has revealed that parents are more worried about the social roles and married life of their daughters with disabilities. In Nepal, there is a stigma against girls staying in their maternal home after their marriage age. As a Nepali saying goes, girls are '*arka ko ghar jane jaat*', meaning girls are meant to go to other's houses, unlike boys, who stay with their parents for life. Similar attitudes towards girls with disabilities in India have been reported: 'one a girl, that too with a disability' (Ghai, 2002, p. 53).

Disability combined with gender creates a state of dual disadvantage for female family members. According to Hickey and Wilson (2017), 'The concept of intersectionality can help explain the compounding nature of how multiple identities and inequities intersect' (p. 89). This concept asserts that the different identities of women (for example, gender, caste, disability, etc.) compound to segregate and oppress them. This concurs with the argument of Shah Thapa (2012) that girls with disabilities face 'limitation along with gender stereotypes' (p. iii). India's case is not much different, as women with disabilities 'are much more marginalised' (Ghai, 2002, p. 53). Essentially, this situation for women with disabilities is comparable throughout Asian countries: 'Eighty percent of women with disabilities living in rural Asia are unable to meet their own needs and are heavily dependent on family and friends' (Handicap International, 2013, p. 1). In these societies, even girl siblings without disabilities suffer, as found in Antony's study in India, where many marriage proposals for the sisters of boys with disabilities 'were turned down because of [their brothers'] disability' (Handicap International, 2013, p. 75).

In South Asian countries including Nepal, girls and women appear to be particularly affected by uneven views of disability in relation to gender, which may be related to their restricted roles. For example, a girl is considered to be able to lead a successful married life only if she can bear a child, because in Nepal, only after the birth of a child does a woman's relationship with her spouses' home become strong and stable. According to Paudel et al. (2018a), 'it is perceived that a girl is secured and settled when she is married, gives birth early and has a surviving child, preferably a baby boy' (p. 4). Therefore, girls with disabilities who are perceived as not being able to settle in their spouse's house generate great anxiety for parents. Girls with disabilities are assumed to be unable to conceive and give birth to a baby and for that reason, in some countries, for example, in India, ‘Women and girls with disabilities are forcibly sterilised and pushed into terminating pregnancies, based on the paternalistic reasoning that “it’s for their own good”’ (Handicap International, 2013, p. 2).

In the West, however, the issue of pregnancies of girls with disabilities is dealt with from the viewpoint of a right to give birth and the caring capability of mothers. In many cases, women with disabilities are not allowed to continue a pregnancy, even if it is desired. Groce (1999) asserts that a married woman with a disability generally does not entertain the right ‘to choose to have and raise a child’ (p. 12). Despite these hurdles, if they give birth, girls have to face the likelihood of their child being taken away by relatives or adopters in the name of providing him/her proper care. However, this research, being focused on children below age 18, did not collect enough evidence to compare with such findings related to mothers with disabilities caring for babies. Another issue raised by this research is the safety of girls with disabilities.

Safety and violence

Parents in this study had concerns regarding the safety of their daughters with disabilities as they became adolescents, fearing sexual abuse and pregnancy. In such cases, parents feared that girls with disabilities would not be able to identify the abusers and also would not be able to defend themselves against them. This finding supports observations from UNESCO’s Global Monitoring Report of 2003: ‘disability limits themselves, making it more difficult for some girls to assess violent situations, to defend themselves and/or flee, or to report incidents of violence’ (Rousso, 2003, p. 10). Such situations position girls with disabilities at increased risk of being abused, and of unwanted pregnancy. In addition, the sadder part in Nepal is, as observed by an earlier study, ‘Violence against women both in the domestic and public spheres (i.e., workplace) is hardly touched by current laws’ (Acharya, 1999, p. 22). This seems to continue to be the case as evidenced by the increased number of reported incidences in the media (The Himalayan Times, 2018).

Comparable cases are reported from rural Africa, where women with disabilities face high rates of sexual violence (Handicap International, 2013). They ‘are often sexually abused and their families, who often know about it or are involved in such abuse, stay silent about it due to fear of further discrimination and stigmatisation’ (p. 2). Even in developed countries like Australia, an earlier study indicates that ‘sex-based harassment … is a significant problem’ (Hastings, 1997, p. 118). A recent publication of the Government of South Australia confirms that children with disabilities continue to be prone to such abuses: ‘it is unclear exactly how frequently sexual abuse of children and young persons with disability occurs, but it is known to be significantly more than those without disability’

(Government of South Australia, 2012, p. 5), and a similar situation is reported in Victoria, another state of Australia: ‘Females with intellectual disabilities are particularly vulnerable’ (VicHealth, 2012, p. 8). Nepal’s case is alarming given the growing number of cases related to rape and sexual abuse in recent years (Starr, 2018). In such circumstances, parents do not want to send their daughters with a disability to school or school hostels particularly when they reach adolescence. This explains the non-enrolment in and early drop-out of girls with disabilities from schools. While this has not yet been researched in Nepal, some studies, such as one from Uganda, report that parents prefer to send their daughters with disabilities to residential schools to prevent the occurrence of violence during their journey to school (Devries et al., 2014). The issue of gender is complex and calls for effective measures to address the marginalisation of girls with disabilities. Strategies such as awareness programs and strengthening of legal rights are potential areas of focus to address current discrimination and these are discussed further in the final chapter.

This research has found a ray of hope in expanding the active agency of girls with disabilities and female family members. Despite the limitations and constraints, the mothers and grandmothers in this research articulated their concerns and desires clearly, dreamt of a better future ahead, were willing to invest for their daughters, were ready to combat adverse situations, and were asking for their reasonable share of rights and responsibilities from the family and society. They shared many instances where they showed their courage and were hopeful for positive results from their efforts. A similar finding was reported by Shah Thapa (2012) that girls with disabilities in Nepal are ‘committed and enthusiastic to go ahead to lead a better life [and] continuously involved in their active agency roles’ (p. ii). Such a positive attitude is an opportunity and a ground for future interventions. Additional detail on the implication of this finding, such as the need for women’s education and empowerment, is provided in the next chapter.

6.2.4 Health care is a bigger priority than education in the early years

This research found that health care is a bigger priority for parents of children with disabilities in the early years as they make dedicated efforts to diagnose and potentially find a cure for their children’s disability. This caused late enrolment of children with disabilities in schools. Education systems in Nepal are not integrated with health and other social care systems, meaning that education professionals need to understand parents’ concerns, including that their first priority is to receive quality health care. Effective and knowledgeable health service providers should encourage parents to actively seek education options for their children. Exploration of the role of the health sector seems crucial in this regard as well as training around disability for rural health workers; these suggestions are discussed at greater length in the next chapter.

Lack of adequate and quality medical services

Poor access to healthcare facilities was an issue for the participants in this research. Medical facilities are not adequate, and their quality is poor, even more so in the rural areas of Nepal. Many factors have contributed to the inefficient medical services including long distances to services, remoteness, shortage of health workers and their absenteeism[25] at service centres located in rural areas, insufficient training of local health workers, and the lack of coordination between services. The distance to medical services is particularly challenging for many developing countries including Nepal where services are not geographically accessible to many. Paudel, Upadhyaya and Pahari (2012), in their study in a rural part of Nepal (Surkhet), found that distance is 'significantly associated with access to health care services' (p. 20). Garha (2017) in his study in an urban location (Kathmandu) also supports this finding: 'Distance alone is a major hindrance for the individuals to seek prompt and timely care' (p. 115). Bennett (2005) argues that distance and geography in Nepal 'also contributes to exclusion' (p. 6). The parents in this research require frequent visits to medical centres that are quite far from their homes, which demand a significant time commitment.

While in developing countries, access to and quality of healthcare facilities is a widespread challenge for all citizens irrespective of their home location and ability/disability, obviously rural and disadvantaged people suffer more. In developed countries, although quality medical services are available in several locations and are accessible to a large section of the population, people with disabilities and those in rural areas have been reported to experience services of poor quality (Deane, 2009). VicHealth (2012), for example, identifies a number of barriers preventing persons with disabilities in Australia from accessing prompt and appropriate healthcare services: 'physical and organisational barriers, including inadequate transportation, failure to provide assistance with communication, and discriminatory attitudes among healthcare staff' (p. 4). To eliminate such situations, policy makers accept the usefulness of the social model of disability, as 'Australian communities work together to improve the social and economic circumstances and the poorer health that people with disabilities experience' (VicHealth, 2012, p. 9), in order to provide 'the same access to health care' for persons with disabilities as all others receive (Deane, 2009, p. 31). In Nepal, this research clearly identified that the healthcare services available are not able to address the needs of persons with disabilities and their families. Parents are not able even to receive basic health care for common sicknesses; health care to meet the needs of children with disabilities is still not a priority throughout health systems, especially at a rural primary health care level. Rural health facilities lack sufficient health workers in general, and lack health workers with even basic training in

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[25] Absenteeism is a usual pattern of intentional, habitual and uninformed absences from a duty or responsibility.

caring for children/people with disabilities; therefore, it is not surprising that parents turn to faith healers and traditional medicines.

While disability is still nominated as a priority agenda item in the health and welfare systems of Nepal, the shortage of medical staff, particularly in remote areas, has been an ongoing burning issue and challenge for the country. Garha's (2017) study in Nepal identifies 'poor demand and supply of services such as workforce' (p. 114) as a key barrier to accessing the healthcare system. Similarly, 'a critical shortage of health workers' is reported as a problem by a WHO study (quoted in Sherchand, 2013, p. 1). Because of this, the ratio of healthcare professionals to the population they serve is low, which further complicates the problem, suggesting that merely the physical establishment of healthcare centres does not guarantee people's access to quality services. Furthermore, absenteeism of medical professionals at the rural healthcare centres is a common phenomenon in Nepal (Sherchand, 2013). An earlier study in Bangladesh also reports an alarmingly high rate of doctors' absenteeism in rural areas. For example, in smaller sub-centres with only one doctor, the absenteeism rate is 74%, meaning there is no one to treat patients (Chaudhury & Hammer, 2003). Such cases demonstrate that the quality of health care in developing countries like Nepal is severely compromised.

Lack of training on disability for rural health workers

As briefly stated earlier, a lack of training for health workers in the area of disability might have also contributed to limited access of the parents of this research to quality health services. Previous studies have reported that health workers employed in Nepalese villages are just distributors of pills and providers of first aid for common sicknesses (Morrison et al., 2008). While health workers in rural Nepal may have a basic knowledge of the causes and manifestations of disability, they do not receive any training related to disability or the social or cultural dimensions of disability. Similarly, literature review revealed that in remote areas of Australia, healthcare providers have been reported to receive little training in the health needs of people with disabilities (Deane, 2009).

In Nepal, while the practice of *sudeni*, a traditional birth attendant, usually females who help rural mothers during delivery, is common and valued, they lack an understanding of the initial signs of disability. *Sudenis* learn the skills required for this practice informally through their own experience and from their seniors and older relatives, which has been supplemented by training in family planning, sanitation and preparation for birth (Thatte et al., 2009). Studies further show that *sudenis* have a 'strong desire to improve their knowledge and skills' (Thatte et al., 2009, p. 607), which means any input provided to them in the form of identification of post-natal or congenital disability is highly likely to lead to positive outcomes.

Overall, the medical situation of children with disabilities and their parents in this study was found to be clearly linked to their educational outcomes. This was obvious in many parents' stories, such as this one: 'When he was small we took him to Lucknow, and Kanpur in India for his treatment, which also caused some delays for his schooling' (Parent, Interview 5). As many parents have to spend significant time in health care for their children, they cannot enrol children in school at the right age. Delayed enrolment has caused many children to leave school without completing even the primary level because of the government policy of age restriction. Children stop receiving the stipend when they turn 18 (DoE, 2016); and, as data from this research suggest, schools cannot afford to keep them without additional financial support. If parents have prompt and adequate healthcare services available close to their homes or at schools, they might enrol their children earlier and avoid such situations. This suggests a need for collaboration and cooperation among different agencies, which is further discussed in the light of its implication for policies and practices in the final chapter.

6.2.5 Parents place high importance on education, yet many children with disabilities do not benefit

Participants' stories collected in this research indicate that they perceive several benefits from education, although not all children with disabilities gained access to schooling. A range of factors such as distance, poverty, severity of disability and lack of coordination between services are identified as barriers for these children's schooling. This section is elaborated under the following subheadings: perceived benefits of schooling, and lack of schooling opportunities for children with disabilities.

Perceived benefits of schooling

Participants in this research believe that education creates opportunities for children with disabilities. In developed countries, school is accepted as a major component of society and schooling as an essential part of the lives of children including those with disabilities. In an Australian study, Deane (2009) asserts: 'Education determines more than a child's economic future – it is also critical to a child's social and emotional development, to establishing a sense of identity and sense of place in the world' (p. 47).

Parents in Vincent and Martin's (2002) study in the UK also emphasised the importance of education as a key to their children's lives and hence as 'a major priority' (p. 119). The findings of this research support these observations. In this research, parents' desire to send their children to school and their view of education as a tool to make their future brighter can be attributed to their increased awareness about education. Several elements might have contributed to raising these parents' awareness and inspiring them to pursue their children's education, such as parents seeing Nepalese people with disabilities as role models and accessing the local media that spreads positive messages about education. The value of role models in educating people is highlighted in some other studies such as the one by Kuca-Thompson (2007) from Western Australia. Kuca-Thompson (2007) points out that a role model can influence individuals, families and the wider society, as people try to bring changes in their own life by projecting the role model's attitudes and values onto themselves. Success stories of high achievers with disabilities gave parents hope for the future and this provides an opportunity for people with disabilities in Nepal to do the same.

Access to media such as radio and television, which has mushroomed in recent years in Nepal, has had a significant impact on people's opinions and perceptions (Dahal & Aram, 2013). Nepal has been recognised for its extensive network of community radios (Bhandari, Bhattarai, & Deane, 2016). Various other studies from Nepal have highlighted the role of mass media in informing 'citizens about the developments and progress of society' (Khanal, 2014, p. 1; see also Banjade, 2007; Dahal & Aram, 2013). According to Banjade (2007), local media in Nepal are operating with the intention to initiate dialogue around the burning issues of society, such as children's rights including the rights to education, social justice, equity and equality, and the empowerment of local people, and to convey positive messages on those issues to the local people. A similar trend is also reported from Bangladesh: 'broadcast media like radio and TV have tremendous reach and influence and play a vital role to build up awareness' (Rahman & Rahman, 2007, p. 6). The expansion of Nepalese media, which has provided a platform for the sharing of progressive political and social ideas, may have assisted these parents to acknowledge the importance of education. In addition, the decade long (from 1995 to 2006) Maoist armed struggle, despite the heavy costs to the nation and people, may have contributed to sensitising and encouraging disenfranchised people at the grassroots or in rural areas and poverty pockets to become more vocal in demanding their share of rights and power (Bennett, 2005).

Likewise, several efforts by the Government of Nepal to ensure all children's rights to education could be another influence on the positive perceptions about education of the parents in this study. For example, Nepal has been a part of concerted efforts initiated by the global community especially since the early 1990s, which include Education for All (EFA) 1990 and 2000, Millennium Development Goals 2000, Sustainable Development Goals 2015 and concurrent commitments for children with disabilities through the popular Salamanca Statement 1994, UN Convention on the Rights of Persons with Disabilities (CRPD) 2006 and Incheon Framework 2015 (Singal, 2016a; UNESCO, 1994, 2006, 2015). Nepal being a signatory to all these commitments; the government initiated several programs such as 'Welcome to School', 'Child-friendly School', 'Minimum Enabling

Conditions', scholarships for marginalised students including children with disabilities, *Dalits* and girls, and 'flexible, mobile and school outreach' programs and so on with a view to reach out to all remote and abandoned areas (MoE, 2009). Such programs also might have contributed to bringing awareness to these parents about education. For example, Nepal's current achievement of access to basic education for 92% of its children has been attained only with the support of almost every family and community in the country, although, undeniably, most of the children who are out of school are children with disabilities. This research showed that most parents do not want to confine their children with disabilities within the four walls of their house; however, in some cases they are forced to do so. They feel they have no choice, as they are overwhelmed due to social stigma, anxiety, lack of support, and being rejected by services such as schools, and eventually they lack the energy to fight for their child's rights.

Lack of schooling opportunities for children with disabilities

As elaborated in the previous chapter, some children with disabilities in this study were rejected by schools and others were forced to enrol well after the usual school starting age, such as in the case of a parent in this study whose son was denied enrolment in a school (Parent, Interview, 14) and another parent, who was asked by a school to bring his grandson with intellectual disability to enrol only when he turned 10 (Parent, Interview, 11). This indicates that commitments made by Nepal in international fora are not necessarily translated into everyday practice. The same situation is reported not only in other developing countries, such as Myanmar (ECDC & VSO, 2015), but also globally: 'children with disabilities are recognised as a group who are least likely to be enrolled in school' (ECDC & VSO, 2015, pp. 29–30). This research found that the non-schooling of children with disabilities is attributable to several factors: stigma and the culture of concealment, distance from home to school, severity of disability, financial constraints and inadequate investment, professionals' attitudes and beliefs, lack of coordination and isolated education provision, schools' denial of enrolment, schools' inability to accommodate children with severe disabilities, and lack of disability-friendly facilities. The next chapter also provides additional details of these findings along with their implications.

Parents in this study reported the fear of their children's disability being noticed leading to discrimination. This could be because of the lack of acceptance and understanding of disability in society. Therefore, some parents preferred to conceal the disability by not sending their children to school. Previous studies such as those by Shah Thapa (2012) from Nepal and Otieno (2009) from Kenya concur with this finding. Similar barriers are present in other parts of the world, for example, in the countries of the Pacific region, according to Sharma, Armstrong, Merumeru, Simi and Yared

(2019). Significant barriers identified in those countries included ‘stigma and negative attitudes towards people with disabilities’ (p. 65). In Kiribati also, attitudes towards children with disabilities are ‘a significant factor in school exclusion’ (Yates et al., 2019, p. 81).

This concealment of disability, however, did not prevent parents in this study from seeking health care, including diagnosis, treatment or cure for their children. They were open to share and talk to professionals but did not necessarily want to share this with their neighbours and communities. In contrast to their contact with the health sector, parents might have feared bringing their children to schools, considering schools as places where from their disability is likely to be known to everyone in the communities, through their peers and educators. Whatever may be the case, this research found there is a need to educate schools and wider communities about the need to respect the rights of children with disabilities.

Distance is another barrier that has caused many children with disabilities to remain out of school. As discussed earlier, for most Nepali parents with children with disabilities, residential schools are the only choice as there is a lack of local facilities for children with disabilities. In addition, despite the provision of three approaches of schooling – special, integrated with residential facilities and mainstream/regular – in Nepal to cater for the educational needs of children with disabilities, children with profound and severe disability are not served by any of these approaches. The majority of children with severe disabilities are forced to stay at home their whole lives. As the existing rehabilitation centres are able to house only a few, this suggests that more rehabilitation centres are required to cater for the needs of children with profound disability.

Parents’ inability to afford the cost of schooling is another barrier that prevents these children from being in schools. Although the cost of tuition, food and stationery are waived for children with disabilities in Nepal (DoE, 2017), the other costs that parents need to bear are transportation costs to commute to and from schools, uniform, and regular or casual medicines. In the areas of this research, the quality of food provided in hostels and other facilities such as sanitation are poor. Moreover, the available resources are not also utilised efficiently, as expressed by focus group participants, such as a head teacher: ‘it would be good if all school teachers receive at least one day’s orientation focusing on the issues of disability. Can’t government do that, when it wastes millions of rupees in the name of inclusive education?’ (R12, Focus group 2). A recent study from Bhutan also reports ‘the lack of adequate resources, facilities, [and] support services’ as challenges to the implementation of special needs education (Subba et al., 2019, p. 43). The lack of funding from the government ‘beyond basic classroom provisions such as teaching materials and teacher salaries’ was reported as common in the past in Kiribati also (Yates et al., 2019, p. 81). The dearth of resources is cited as a barrier even in developed countries. For example, while 'lack of appropriate funding, classroom support and specialised equipment are also enormous barriers to educational opportunities' for children with disabilities in Australia (Deane, 2009, p. 47), Nepali schools lack even sports, extracurricular, cultural and music-related materials (let alone adequate and qualified trained teachers) which are essential for the development of all aspects of students through their full participation in instructional, physical and cultural activities. This could be due to the lack of commitment of policy makers, as commitment on their part could positively contribute to the advancement of special needs education by addressing issues of resource allocation, professional development of pre- and in-service teachers, and the creation of disability-friendly infrastructure.

The progress that has been noted in the schooling of children with disabilities in this research, however, is limited to physical integration. This suggests that isolation continues to be a dominant phenomenon in Nepal in practice. This aligns with a recent study that teacher attitudes, behavioural problems, communication, bullying and violence are barriers affecting special needs schools in Nepal (Plan, 2014). As special needs education, particularly inclusive education, is linked to the values of human rights, ethics and social justice, this suggests a need for a higher goal of creating 'an inclusive and democratic society' (Johansson, 2014, p. 1220). While inclusive education in developed countries was initiated in response to the rights-based movements, parents' and professionals' stories in this research suggest that in Nepal this was not the case. The advent of inclusive education in Nepal was basically a response to development partners' agendas and resourcing (CERID, 2004; Kafle, 2002), while in developed countries it included parents' and families' struggles to ensure the rights of children with disabilities (Turnbull et al., 2000). Thus, these initiatives of inclusion in Nepal are not authentically rooted in demands from the ground and are not necessarily embraced by policy makers, as evidenced by their indifference to allocating adequate resources or creating robust mechanisms to enforce the existing policies. Hence they may not have recognised children's rights and embraced true inclusion in schools.

6.2.6 No parent-friendly school structures: Barriers to parental engagement

This research has highlighted a number of barriers that prevent parents from engaging in schools' activities, despite their willingness to contribute in some way to their children's education. The differing worldviews of parents and professionals and uneven hierarchical relationships were the two most prominent factors impacting parental engagement in the study site. In addition, other underlying factors such as inconducive policies, stigma, parents' limited resources and distance also continue to impact parental engagement.

Differing worldviews of parents and professionals

Parents and professionals had different viewpoints with regard to parental engagement in schooling, as evident in the parents' stories, such as: 'Whenever we will be called [by school staff], we will come. If there is some work in school and if sirs ask us "let's do this"; then we won't say "no"' (Parent, Interview 5) as well as in professionals' accounts, such as: 'We haven't organised a separate meeting for parents of children with disabilities; we don't have that practice for them. I think this is not made mandatory, too; there is not any ordinance or rule to do that' (R3, focus group 1). While the motivation or willingness of parents to work together with schools and be involved in their children's schools may be attributable to the collective culture of Nepali society, this is not easy for educational professionals to follow, as they must follow the government policies which do not necessarily encompass such cultural practices. Nepali family structures and other social processes (rituals and processions) are heavily rooted in the collective belief system. People often refer to a Sanskrit maxim, '*padher bhanda parera janinchha*' (we know more through participation than studying), to educate their offspring about the importance of 'participation'. However, this may not be applicable to government employees such as teachers because, as official development workers, they must follow the government's instructions and are no longer bound to follow local belief systems. While parents and families subscribe to traditional beliefs, professionals and school staff as an agency of the country's modernisation process are expected to implement developments as per central policies (Shrestha, 1998). This has created a schism between parents' desire to contribute and school processes.

Parents' and teachers' work environments are different. While parents are guided by traditional conventions and practices, teachers are guided by the government development agenda. Parents are likely to experience participatory practices through various social activities. For example, people gather in one place for a discussion before arriving at any conclusion on issues such as observation of rituals, festivals, local road maintenance, management of drinking water, forestry and irrigation. Nepali development initiatives are guided by modernist views that do not value people's common belief systems including collectivism and participation. A side effect of the country's development initiatives is that such local values are beginning to disintegrate (Shrestha, 1998). Schools also, as a part of the modernisation process of the country, do not model these values and beliefs. Shrestha (1998) views Nepal's modernisation approaches as inappropriate as they do not acknowledge lay people's ability, wisdom and potential in developmental efforts. Even in developed countries, there can be different perceptions about parental engagement between teachers and families and communities. In Australia, for example, Carrington and Robinson (2006) note that 'schools frequently refer to parents as partners in the educative process but the nature of the involvement of families is, in many schools, superficial', which may be because 'parents are seen to be more part of the problem than the solution' by the educators (p. 328).

In the Nepali education sector, there was a hope for increasing access for children with disabilities to education with the introduction of special needs education during the Education for All era 1990–2000 and 2000–2015. The government promised to attain this by employing strategies such as increasing partnership with local communities and parents (MoES, 2001, 2003). However, parents remained largely uninformed about the government's intentions and about their anticipated role in the success of such programs. Moreover, school authorities did not exhibit faith in parents' ability to make a contribution. This often led poor and illiterate parents to perceive themselves as incompetent actors, and contributed to reducing their self-efficacy, meaning they lost faith in their ability to contribute to school life. In many cases, professionals' perception of the incompetence of parents and parents' feelings of inferiority led to limited engagement, which is further fuelled by the hierarchical relationships between parents and professionals.

Unequal relationships

The relationships among parents, education professionals and government officials in this research clearly have hierarchical foundations. In Nepal, government officials or civil servants are regarded as more privileged than teachers (Dahal, Uprety, & Subba, 2001; GoN, 2000), as the former group's position is considered high and they hold most power in decision making regarding school matters. In a similar vein, central officials hold more power than local level officials, teachers hold more power than parents, and community leaders hold more power than ordinary people. Feelings of domination or submission therefore always operate among school-level professionals in a hierarchy defined by the context so that when school professionals deal with parents and local people they feel superior and when the same stakeholders deal with government officials there is a feeling of inferiority (Carney et al., 2007).[26]

Hierarchical structures in Nepal are reflected in communication, language use, behaviours and attitudes of the people involved in any interaction. This research reveals that, due to the uneven power relationships between parents and professionals, the type of communication operating between them is top down. There could be a view inherent in people at upper levels that more equal communication could threaten the prevailing social and power structures. Although some changes are occurring in Nepal currently, possibly due to political transformation, parents still have

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[26] This was one of the reasons why I separated the research participants into different groups for focus group discussions during my field work, so that I could avoid the dominance of one kind of professional over the others during those interactions.

thoughts such as ‘we are poor, and we have a child with a disability, what we can do?’ (Parent, Interview 4).

In general, Nepal has a ‘*thulaa badaa jaanne sunne*’ culture (meaning they who are at the top know best). This research found that parents have an image of every teacher as a *guru* or *guruma* that literally implies ‘authority’. Teachers are viewed as important persons in Nepali society, who are superior to parents. Although parents in this study clearly held schoolteachers, head teachers and bureaucrats in high esteem, they may not have necessarily understood the conventional modes of speaking and behaving, as expected by education professionals who occupy a higher rung in the hierarchy. Cultural practices, such as unconditional respect to people in higher positions, have contributed to widening the gap between parents and teachers. Hence parents are hesitant to meet and talk to teachers. Therefore, parents attending schools in this research chose to meet and talk to *aayas* only. *Aayas* as low-paid, less-qualified personnel, who were only given the responsibility of taking care of children in hostels, might have been considered by parents as of equal rank. This research found *aayas* were an important contact person for parents. While *aayas* were trying their best to serve the needs of children and their parents, as they were underpaid and untrained, they sometimes lacked motivation. The research recognises that the *aayas* should be provided with appropriate training and support, and their grievances related to their compensation should be addressed.

Parents in this research believed that teachers know everything, and that they did not have much to contribute. In a participant’s words: ‘the teachers are far more knowledgeable than us. What would we have to suggest to the teachers?’ (R5, Focus group 1). Therefore, parents do not want to question teachers’ ability and their conventional power; they even tend to leave decision-making power in the hands of educators. In addition, people’s beliefs about work done by professionals, such as ‘what they do is a good thing’ (Parent, Interview 4), further legitimises the centrally oriented mentality and centralisation of power in decision-making processes. This mentality does not challenge the status quo and existing practices. From this perspective, school committee members or bureaucrats are eligible to make decisions on behalf of parents, and they are even responsible for defining the interests of the parents.

Moreover, the school environment does not encourage parents’ involvement; their advice is seldom sought. For example, the professionals in this research even criticised parents for not having the knowledge and skills needed to contribute to school matters. However, viewing parents and professionals through a strengths-based lens could have contributed to creating equal relationships. This research notes that both school professionals and parents have expertise in certain areas. For example, while school professionals are experts in technical areas, such as content and pedagogy, and know what approaches are effective for the learning and growth of children with disabilities, parents are knowledgeable about practical aspects, such as children's personal needs, as they know the nature of their children, and their likes and dislikes. This implies that both parties have roles to play for positive outcomes of children with disabilities.

Other underlying factors limiting parent engagement in schooling

In addition to differing worldviews and unequal relationships between parents and professionals, this research revealed that unconducive government policies, general attitudes and stigma associated with disability, and parents' limited resources were other underlying factors limiting parents' engagement in schooling of their children with disabilities.

For example, there is no mandatory policy to organise periodic meetings and assemblies of parents of children with disabilities in Nepal. Although parents in this study sometimes visited schools, they were not necessarily invited, and the scope of such visits was very limited, for example, to observe the wellbeing of their children staying at hostels. However, since education professionals articulated the importance of parental engagement during focus group discussions, it seems that it is not their intention to exclude parents from being involved, but they may lack sincere conviction about its importance. As long as the provision for parental engagement or parent–teacher partnerships are not enshrined in policies, schools are not bound to guarantee such representation in practice. Importantly, this research noted that policy ambiguity has become an excuse for professionals and school personnel to hide their inability to involve the parents of children with disabilities in school matters.

Some legal provisions recently initiated, such as the formation of school management committees (SMCs) with a representation of parents of children with disabilities in integrated schools, were also found to be impractical because these schools are sparsely distributed across the nation, and because parents of children with disabilities often live away from the school locations. Due to geographic distance, it is not possible for these parents to devote their time and resources to their children's schools. In addition, although many students with visual and physical disabilities or mild or moderate types of other disabilities are enrolled in regular or mainstream schools across the nation, the representation of their parents in those mainstream schools has not yet been guaranteed. The other parents representing the SMCs, despite having some power to influence schools, do not consider the needs of children with disabilities when making decisions, such as recruiting teachers, nor do they know the status and needs of the non-enrolled special needs children in their community.

The lack of policies that are conducive to parental engagement in special needs education could be due to the very nature of Nepali society guided by hierarchical norms that may not acknowledge egalitarian values and may inhibit the initiation of policies that favour grassroots people. Nepalese policy makers are criticised for not being grounded in local knowledge and the existing conditions (Dahal, 2002; Edwards, 2011) and hence professionals do not understand what families of children with disabilities are going through. However, the process of developing policies that favour these families and grassroots people might not be simple and may not be 'achieved by fiat but through a lengthy learning process', in the words of Dalin (2004, p. 5).

Moreover, researchers in Nepal note that, even if policies are in place, it is difficult to ensure their implementation in practice, as there is a weak link between policies and actual practices (Edwards, 2011; Regmi, 2017). A similar situation is reported in India by Rose (2018b), where the 'critical relationship between policy and practice is ill-defined and that this is inhibiting the ability of schools to address the needs of a diverse population' (pp. 1–2). This gap between policy and practice can be explained by using Argyris and Schon's 'theories of action' (cited in Lewis & Naidoo, 2004, p. 100). According to this theory, what is expressed in policy documents are espoused theories, which may not necessarily be translated into actual practice, or theories-in-use. This is why people's empowerment, authentic participation or willingness to give people a voice, which may appear in Nepali policy documents, have not been translated into practice. In such cases, idealistic notions and sophisticated wording in policy statements become mere showcasing or lip service as they are limited to espoused theory only.

As discussed above in Section 6.2.2, the stigma associated with disability has created discrimination not only against children with disabilities, but also against their parents, schools and teachers, as also is the case in many other countries (Otieno, 2009). These perceptions obviously affect how people see their roles and what they expect of parental engagement in their children's schooling.

Parents' limited financial resources and distance are also factors affecting parental engagement in this research. The research has noted parents' need of extra resources (time and finance) to commute to the distant residential schools. A similar case is observed in the residential schools of rural South Africa also, as Ngwenya (1996) reports: 'because parents are not part of the immediate school community the concept of "parents as partners" is difficult to achieve' (p. x). The finding also corroborates the study of McGill, Tennyson and Cooper (2005) in the UK in that they reported significantly less frequent parental visits to children's schools due to distance and cost.

Moreover, when survival becomes the core business of families, engagement in schooling is peripheral. This is also the case in other developing countries, such as in India: ‘For the majority of these children and their families, subsistence takes precedence to education as they have an immediate need for food and shelter’ (Das & Shah, 2014, p. 574). In the USA, as observed by Baquedano-López et al. (2013), parental engagement is very much shaped by ‘social and cultural resources’ (p. 160). Therefore, this research’s finding is consistent with studies from both developing and developed countries.

Workloads of parents equally contribute to their lack of engagement in schools, although they were happy to make the effort to attend the school if they were invited. On the other hand, school professionals did not take account of parents’ difficulties; instead they readily blamed parents for not attending the school, although they had only rarely invited parents to attend schools. Therefore, this research suggests that schools need to be more be considerate of the problems of parents compounded by poverty, workloads and distance. In this context, schools need to be more flexible to adjust their programs and schedules to meet parental needs. Letters, newsletters, reports and phone calls, as suggested by the parents in this study (Parents in Interviews 1, 5, 6, 11), are other ways that schools should consider to engage parents, especially when many parents are not able to get to schools given the distance barrier and when schools do not have sufficient staff for them to visit parents’ homes.

Despite multiple challenges in schooling their children with disabilities and parental engagement in their children’s schools, parents in this study did not give up. They would walk any possible avenue for the betterment of their children and commit to their children’s wellbeing and education. This research has identified that they explored options, increased their awareness, gained confidence, strived for success and wanted to be empowered. It is evident in the data that they are keen to be involved in schools’ activities, meet other parents, and contribute to schools with their expertise, knowledge and resources.

6.3 Chapter summary

This research found that parents and families of children with disabilities in Nepal are in a state of confusion as they try to make sense of the implications of their child’s disability. The findings demonstrate that parents underwent several stages of uncertainty including exceptional distress, sorrow and challenges as well as occasional joy and hope in their journeys of raising their children and connecting with their children’s schools. Due to the inadequacy of services for families in remote areas, parents are further pushed to live in isolation and deal with their children’s disability on their own, despite limited support and entitlement from the government and occasional activities of non-government agencies. Moreover, available support structures such as services for health, education, early intervention, protection and information (such as information about the availability of schools for student with disabilities) are poorly functioning. These situations contribute to additional grief and confusion for parents and families.

In addition, the perpetuating dominant patriarchal culture of Nepal places greater burden on female members of these families, including girls with disabilities. Although both parents and professionals believed in the extreme importance of education for children with disabilities, there was inadequate government support for these children to access appropriate education. In the absence of coordinated services, parents’ concern for their children’s health care precedes education for many children. The significant findings are that, despite various difficulties and barriers, parents are invested in their children’s wellbeing and education; and are interested in visiting the school, participating in school meetings, and contributing their knowledge, expertise and available resources. However, due to schools’ indifference towards parents’ willingness to invest in their children’s education, parents’ potential remains untapped.

This research has identified a number of obstacles hindering parental engagement in schools including prejudice against local folk wisdom, professionals’ passivity, social hierarchies, mentalities of dependence and reliance on central government, lack of resources, and gender inequality. In such a context, we need to find ways to engage parents, make them feel welcome to attend school celebrations, be hospitable, and assist them to feel comfortable. In the next chapter, I discuss the research findings with a focus on implications for policies and practices. I also address the trustworthiness of the research findings and the limitations of the research and provide a *posteriori* reflection prior to a concluding statement.

CHAPTER 7 - DISCUSSION, IMPLICATIONS AND CONCLUSION: BRIDGING THE GAP AND TAPPING UNTAPPED POTENTIAL

> **Dreaming**: A great Taoist master once dreamt that he was a butterfly fluttering here and there. In the dream he had no awareness of his individuality as a person. He was only a butterfly. Suddenly, he awoke and found himself laying there, a person once again. But then he thought to himself, 'Was I before a man who dreamt about being a butterfly or am I now a butterfly who dreams about being a man?'[27]

7.1 Chapter introduction

This chapter discusses the issues and implications arising from this research, which aimed at capturing the experiences and insights of the participants, particularly the parents as they care for their children with disabilities and seek to connect more effectively with schooling. As discussed in earlier chapters, a relational approach to research was the foundation for capturing in-depth experiences, insights, concerns and opinions. Parent participants were interviewed in their own context, using their language and creating a space for their rich stories of experiences through informal conversations. In addition, interactive vignette-based focus group discussions were similarly used to elicit detailed and rich data from local professionals. In the previous chapters, research participants' stories have been expressed through case study portrayals and theme-based narratives, which followed by the interpretations of findings in the light of their contribution to existing knowledge about parents' engagement in their children's schooling in Nepal.

Given the potential for the findings of this research to enhance parental engagement and educational options for children living with disabilities in Nepal and the necessary link between theory and practice on the ground, discussion and implications are interwoven in this chapter. As such, this research offers valuable information for researchers, policy makers and education professionals who seek ways to support children with disabilities, their parents, families and local communities. Insights from both groups of participants (parents and professionals) make important contributions to the recommendations made in this final chapter. Following this, the scope for future research, trustworthiness of the research, limitations of the research, a *posteriori* reflection and final conclusion are presented. To recap, the main research question and sub-questions are the following:

What are parents' experiences of and perspectives on caring for their children with disabilities and attempting to connect with their schooling in a western region of Nepal?

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[27] A Taoist story from *Zen stories to tell your neighbours* (pp. 18–19) (Retrieved on 25 March 2019 from http://www.arvindguptatoys.com/arvindgupta/zen-for-neighbours.pdf).

- How do parents describe, understand and feel about their experiences of caring for and connecting with the schooling of their children with disabilities in a western region of Nepal?
- What are professionals’ perspectives on parental engagement in the education of their children living with disabilities in this western rural context?
- What are enabling and restrictive factors associated with parents’ engagement with schools?
- How can the outcomes of this research contribute to improving policies and practices for improved educational options for children living with disabilities and parental engagement in Nepal?

7.2 Discussion and implications of research findings

Interpretation of the findings in the previous chapter led to the identification of a number of key issues for discussion. This research has demonstrated the need for:

- bridging folk wisdom and modern scientific knowledge;
- social and psychological supports for parents;
- awareness and empowerment programs for families and professionals;
- women’s education and empowerment;
- inter- and intra-agency cooperation; and
- fostering inclusion and better school practices.

The research also highlights the importance of policy reform to initiate, implement and sustain each of these suggestions and reforms. Moreover, the internalisation of the reforms at individual and institutional levels is equally important to bring about changes in existing practices. Each of these topics are discussed in turn.

7.2.1 Bridging folk wisdom and modern scientific knowledge

Given the key finding of this research that parents of children with disabilities in the studied region in Nepal are as yet an untapped resource, it would appear that bridging local folk wisdom and modern scientific knowledge has much potential to meet parents and education professionals where they are and also extend their knowledge. The problem in Nepal lies however in the policies and attitudes of professionals who advocate for scientific knowledge, without giving regard to local wisdom (Bista, 1991; Dahal, 2002; Dahal et al., 2001; Shrestha, 1998; Raut & Khanal, 2011). Professionals’ worldviews are in the main based on modernist and scientific thinking, which often conflicts with traditional knowledge. For example, in the context of health services in Nepal, Raut and Khanal (2011) assert: ‘Folk medicine employs principles and practices sourced from this indigenous cultural development … [still, it] is an *unofficial* health related practice’ (p. 878, emphasis added). In general education and other professionals behave as if the existing traditional way of knowing has nothing to offer, thus missing the opportunity to create meaningful connections and relationships upon which to build positive partnerships between home and school.

While this research found existing concurrent practices of traditional and modern systems at the level of ordinary people, there is a paucity of reliable research to establish the possibility of combining them at the experts’ level. Unlike lay parents, such as the participants in this research, experts and professionals tend to choose one belief system at the cost of the other. Internationally also, scholars argue that practices grounded in so-called modernism have lost their power to address local problems, mainly because they do not acknowledge folk realities (Dalin, 2004; Chambers, 1998; Fullan, 2001). In line with this, Nepali scholar Dahal (2002) argues:

> The whole process is rooted in western social science theories, application tools and intellectual assumptions. The policies therefore, have failed to grasp the diverse realities created by the predominantly agrarian society of Nepal with its myriad of hierarchies. (p. 36)

Thus, many people in positions of power are inclined towards borrowed knowledge, which in most cases comes linked to foreign aid, regardless of its effects and relevance to national and local life (Bhatta, 2011; Maudslay, 2014). This research, however, argues that policy makers in Nepal need to bring modern as well as traditional/religious ways of understanding or of healing disabilities together to support children with disabilities and their parents.

From a relational perspective, both traditional and scientific knowledge have merit, even if they sometimes contradict each other, which often leads ultimately to growth and development. Whatever the country or context, education professionals and experts need to acknowledge parental understandings about disability, deeply contemplate how parents and families make sense of disability, and what assists them to make such meanings, which may require changing how professionals approach local conceptions of reality. Thus, disability should not be understood as a simple notion grounded in one particular belief or theory. Disability is an intricate, complex concept, particularly if we truly want to acknowledge the perspectives of the people residing in rural villages. This further indicates that anyone wishing to work with parents of children with disabilities requires this understanding. Therefore, a bridge to connect two worlds is required which should take cognisance of ordinary people. From this research, I argue that reconciliation between old and new knowledge is possible, timely, relevant and necessary.

Any interventions initiated to address the needs and concerns of vulnerable families need to build on the existing knowledge and practices indigenous to those families, where 'Indigenous implies originating from and naturally produced in an area' (Chambers, 1983, p. 83). To truly appreciate indigenous folk wisdom, we need to work closely with families and live within their communities (Pini et al., 2015). This follows that service providers must go to the ground level to meet families, assess disability circumstances, and sensitively suggest supports and interventions tailored to their needs, such as early medical intervention, government assistance, and accessible means of transportation to hospitals available in their areas.

To integrate local knowledge in professionals' practices, participatory approaches are needed. Through participation, local communities can contribute to any professional-initiated interventions with their knowledge, capacity and resources which they have accumulated from age-long experience and engagement with their realities. Efforts should not be limited to accepting and acknowledging the differences and cultural constructs of parents but should also provide a forum in which they can discuss their experiences and voice their concerns. In essence, it would also be preferable for professionals to consult with communities prior to moving forward with any initiatives, if they want to make them relevance to the communities' needs. Such a recognition of diversity in any community encourages local wisdom and the respect for local worldviews.

The use of indigenous knowledge in combination with modern knowledge is becoming more common in some countries such as Australia (Burnie, 2019; Condie, 2019; Oliver, 2013), Canada (National Collaborating Centre for Aboriginal Health [NCCAH], 2013), Papua New Guinea (Mercer, Kelman, Taranis, & Suchet-Pearson, 2010) and New Zealand (Hickey & Wilson, 2017). For example, in the context of mitigating the effects of natural calamities, Mercer et al. (2010) report that communities in Papua New Guinea have been using a participatory and integrated framework that utilises both lay people's knowledge and modern knowledge to reduce the vulnerability of communities affected by natural and environmental hazards. In addition, the following view from the Director-General of WHO also supports such a combination in healthcare systems:

> The two systems of traditional and western medicine need not clash. Within the context of primary health care, they can blend together in a beneficial harmony, using the best features of each system, and compensating for certain weaknesses in each. (quoted in Oliver, 2013, p. 5)

In this context, this research demonstrates that externally designed interventions and tools should prioritise local perspectives when attempting to address families and communities' needs. 'One-size-fits-all' policies, issued by central agencies, which often do not succeed in incorporating contextual factors, have been noted to fail (Alegria, Atkins, Farmer, Slaton, & Stelk, 2010). Instead, an engaging approach that focuses on ‘consulting community members and respecting local knowledge and decision-making processes’, by which we demonstrate ‘our willingness to learn’ from laypersons from remote areas can be useful (Morrison et al., 2008, p. 8). Equipped with such attitudes, professionals will not be imposing their dispositions and ideas; rather suspending their prejudices and stepping back from being unnecessarily judgmental and importantly developing respect for local knowledge. This means, in the words of Morton, Higgins, MacArthur and Phillips (2013), ‘changes have to be made at deep levels, not just at the level of technical adjustments’ (p. 759). Moreover, parent-friendly ways, such as relational methods, case study portrayals and narrative approaches, as used by this research, could be of great help while working with parents to bridge the gap, incorporate local wisdom, and even create stories linking with the scientific developments, so that parents can grasp the meanings inherent in modern scientific development more easily.

7.2.2 Social and psychological supports for parents

The research reveals that, due to a lack of quality and adequate support, parents are forced to shoulder their responsibilities using their own resources. There is only minimal support from the government, and certainly no evidence of availability of psychological support for these parents. During my home visits, I observed some children with severe needs, for example, some needed help even to lie down on the floor, while others were difficult to manage behaviourally and required a guardian to be with them all the time. Situations like these drastically reduce the productivity of the families and lead to great hardship. These parents clearly need tangible supports, for example, rehabilitation services for children with profound impairments. In addition, tangible supports can be a form of psychological support for parents as they feel their needs are being addressed and they are not alone in raising their child.

Due to a lack of adequate services, such as diagnosis and early intervention, parents in this study were frustrated. This could have been prevented by the proactive actions of professionals working at local levels. In some cases, as disabilities caused by malnutrition, accidents and injuries are preventable if identified promptly, so, early detection is essential. There is evidence that ‘in many contexts 50% of disability is a result of largely preventable factors’ (DFID, as quoted in Singal, 2015, p. 5). In addition, as diagnosis of some cases such as autism is difficult and complex, appropriate training is needed for the professionals involved such as medical workers, teachers, early childhood development facilitators, health workers, *sudenis* (traditional birth attendants), faith healers and social workers.

The government has mandated district-level institutions – health posts, assessment centres, and women’s and children’s centres – to recognise the early signs of disability and design early intervention measures. However, these services do not reach remote locations. This problem is intensified if families live far from the district headquarters. Professionals based at the district headquarters at the service delivery end tend to serve the immediate surroundings, despite being mandated to cover all regions. This could be because of travelling difficulties and costs associated with travelling. Even more disappointingly, mechanisms to provide information about existing services are lacking. This research revealed that many parents did not even know about the schools offering special needs education in their locality. The government has a policy of free education for these children but parents' perceived reluctance to send their children to school might be due to their ignorance of this provision. As identified in this research, teachers visiting homes can be an effective strategy to inform parents about local services and resources which are available for these parents and their children with disabilities.

As the assurance of the availability of minimum services nearby is important, government services should extend to rural remote areas. In addition, decision makers need to explore the possibility of providing social protection, insurance, employment, community health volunteers and coordinated services to persons with disabilities and their family members. For example, for coordinated services, information about available medical support systems regarding disability can be provided to parents through schools. Similarly, after the identification of the early signs of disability in children, local healthcare providers can provide additional information in relation to appropriate medical or education services.

The findings from this research indicate that in actuality disability is essentially viewed as a domestic concern given the lack of external support and inaccessible professionals' help, and therefore, in many cases parents are left alone to live and deal with their children's disabilities. Given the limited health services, resources and infrastructure in Nepal, even more so in the remote areas, other support such as emotional, psycho-social or respite support for these parents, commonly available in developed countries, is a distant reality (Jack, 2016; Mackay, 2003; Sajjad, 2011). Sajjad (2011) notes that in Pakistan religious and spiritual practices are often the only form of psychological support. This finding is certainly of relevance in the context of Nepal, as highlighted in this research, suggesting professionals connected with parents should have respect and commitment to the existing traditional and religious practices and contribute to linking old and new practices.

Psychological and emotional support at critical times assists parents to cope with issues arising from the disability and assists them in managing their subsequent stress (Chien & Lee, 2013; Mackay, 2003; Sajjad, 2011). Some parents' stories in this research provided examples of feelings of relief resulting from support from head teachers, teachers and healthcare professionals. These illustrations exemplify the beneficial effects of professionals' support for families. A qualitative study from New Zealand has similarly found that 'timely help, such as specialist support or a community programme, had a significant impact on their ability to regain control and confidence' (Jack, 2016, p. 145). Similarly, in China, psychological and emotional supports are viewed as 'significant mediators in reducing the tensions and anxiety of these caregivers' (Chien & Lee, 2013, p. 22). Moreover, these interventions are helpful in that they assist parents to make appropriate decisions in regard to their children's education, health or future careers.

However, support should be tailored to meet the needs and circumstances of parents and families of children with disabilities, as their challenges and strengths vary. Frontline service providers – both education and medical professionals for example – need to have a deeper understanding of the nature of grief experienced by parents and their needs, which may require a range of support services. Just as counselling, yoga, meditation, prayer and social activities have been shown to be beneficial in dealing with grief (Sajjad, 2011; Teixeira, 2008; Sagula & Rice, 2004; Furnes & Dysvik, 2010), policy makers and professionals or local CBR programs working closely with these parents need to consider these measures to support parents dealing with the challenges of raising their child with disabilities.

As suggested by parents in this study, parent-to-parent conversations and meetings can also serve as a psychological support as there are benefits to be gained from learning about others' experiences. The support is effective and enduring when a parent facing similar circumstances discusses a concern with another parent. Furthermore, when parents share the achievements of their children other parents living in similar conditions are also interested as potentially this provides them with a sense of hope for their own child. Moreover, when they sit together and converse, they feel calm and relieved. This implies the need for regular parent-to-parent meetings. Schools are well-positioned to facilitate such meetings for parents and it should become a priority for schools to plan for such meetings.

7.2.3 Awareness and empowerment programs for families and professionals

This research underscores the importance of awareness programs targeted to parents as well as the professionals who are deployed to serve them. In addition, since simple awareness programs that disseminate information about government policies and programs are not generally enough, these need to be supplemented with empowerment interventions, which should aim at building the capacities and confidence of parents and family members, so that they can actively take the initiative and make decisions on their own. As evidenced in the data in this research, the parents felt powerless and hence vulnerable to exploitation. Empowerment interventions could be beneficial as they aim to improve the lives of people, increase people's access to resources and develop confidence so that they are able to exert more control over their life circumstances (Byrne, 2001; Cavalieri & Almeida, 2018; Luttrell, Quiroz, Scrutton, & Bird, 2009). According to Cavalieri and Almeida (2018), empowerment redistributes social power and control over resources in favour of disadvantaged sections of society. My research agrees with Pradhan and colleagues in Nepal, who suggest that the target of empowerment programs should be people in 'miserable economic situations, low education status, extreme socio-political disempowerment and exclusion and restricted access to resources and opportunities' (as cited in Acharya, 2007, p. 42).

Further, participation of parents in decision making is considered crucial for empowerment. Itzhaky and Schwartz (2000) in Israel found 'a significant relationship between client participation and empowerment, particularly with regard to involvement in decision-making processes' (p. 25). In addition, they observed 'involvement in decision-making processes', 'representation of the people with disabilities and their families' and 'sense of belonging to the community' as effective means of empowerment (pp. 25–26). Therefore, parents of children with disabilities should be encouraged to participate in school programs especially when the issues related to their children are on the agenda. To this end, more encouragement for parents to go beyond participation to advocacy for their child may be required. To allow this to happen, policy makers, professionals and facilitators of parents' awareness programs need to be responsive to this consideration.

Certainly, schools and teachers also experience difficulties, especially when parents have unrealistic expectations or when they are perceived as too demanding. In such cases, awareness and empowerment programs are needed to help parents have more realistic demands and expectations. Moreover, given the extent to which for example school communities become a source of stress for parents since so many people view disability as a stigma, there is a need as this research has identified to increase understanding about disability issues in communities, including amongst medical and education professionals. Some NGOs have developed successful awareness-raising programs for a range of people involved in the care and education of children with disabilities, which are however mainly in existence in urban areas. For example, Resource Centre for Rehabilitation and Development, an NGO based in Bhaktapur, Nepal has produced and used a number of resources on information sharing, human resource development, capacity building and advocacy targeting to parents, communities and practitioners.[28] Future awareness and capacity development programs for

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[28] These resources are available at https://rcrdnepa.wordpress.com/nepalese-disability-policy-documents/reports-2007-2008/

parents and professionals residing in rural locations can seek relevant information in these resources.

In addition, professionals' roles are crucial for the empowerment of parents. This research has revealed that the existing hierarchical structures in Nepal contribute to top-down communication between families and professionals representing schools or governmental institutions. According to Servaes, Jacobson and White (1996), traditional forms of communication are 'vertical, unilateral, authoritarian and top-down' (p. 11). However, dialogical or horizontal types of communication have significant potential; parents and professionals can use them to share aspirations, values and feelings, to develop knowledge and skills and to acquire collective power.

In order for the partnership to flourish, there is a need to foster mutual understanding and respect all voices, for which horizontal or dialogical communication between participating agencies should be a focus. Initiating such communication requires challenging the existing vertical, unilateral, anti-dialogical and authoritarian communication practices and replacing them with horizontal and dialogical practices, as recommended by Freire (1970; 1974/2005), which may not be as easy as is suggested here. It will require professionals to be friendly and honest and to listen to people (Porter, 2002). Burrows (2004) suggests that 'compassionate communication', which calls for sensitivity, understanding and empathy, is needed to foster collaborative working between parents of children with disabilities and professionals at schools. As discussed in the literature review, essentially, genuine engagement requires a flatter school structure in which agendas are defined mutually in the interests of both professionals and parents, and power and authority are shared by them. If the authority of knowledge, voice and decision making rests solely on the educators, parents just become the audience or spectators, fundraisers, supporters and event organisers. However, in order for them to become empowered, professionals need to recognise them as valued members, contributors, opinion providers, decision makers and leaders. This requires the creation of a supportive and conducive environment where parents can share their knowledge about their child with that of teachers and where they are encouraged to engage in all activities of the school: planning, delivery of services, evaluation and benefit sharing.

As discussed in Chapter 2, professionals should ideally be open to move from power-over to power-with and finally to power-through relationships with parents (Luttrell et al., 2009; Turnbull et al., 2000). This may require a change in the existing traditional relationships with parents, in which professionals are supposed to be at the top of the hierarchy. If parent–professional relationships become more equal both parties will benefit from each other's wisdom, both folk and professional. In such situations, Turnbull et al. (2000) argue, 'power or capacity also becomes a limitless resource for everyone in the partnership' (p. 642). If professionals can recognise that they do not lose anything by respecting parents as equal partners, both can take advantage, through a synergetic relationship that builds on the other's capacity and potentiality. These approaches are not resource intensive either; rather they rely on a shift in attitudes which are in the control of both professionals and parents; with professionals needing to develop their listening skills and respect for families and a belief that parents have the ability to parent their children effectively, and parents needing to develop more confidence and advocacy skills.

Moreover, this research has found that it is not only parents whose potential is not utilised. Similarly, teachers in special needs schools, who have deep experience of working with children with disabilities and may have been equipped with the practical skills necessary to solve the problems of their schools, are not also consulted by school leaders. Schools in Nepal, under the current decentralised management framework, are able to devise and implement their own school improvement plans. In this respect, school leaders need to draw on the potential and resources of these teachers by empowering them to contribute to schools' annual and periodic planning, for example.

Therefore, proactive action from school leaders is needed in order to reflect in schools' planning and programs the needs, concerns, interests and strengths of parents, families and teachers of children with disabilities. With such approaches, not only schools, but healthcare systems and other institutions mandated for local services can also take benefits of local resources.

7.2.4 Women's education and empowerment

This research has highlighted differences in the experiences of male and female members of families living with children with disabilities, with mothers and girls being more vulnerable and distressed than their counterparts, and with more responsibilities being placed on the shoulders of female family members who need more support. The research recognises that interventions should be targeted to empower women and uplift their lives, without which it is not possible to fully address the problems of families living with children with disabilities. Other studies have also viewed women's empowerment as a prerequisite for the smooth and healthy functioning of families already experiencing adverse conditions (Klugman et al., 2014) since empowerment helps promote 'the capacity to make decisions about one's own life and act on them to achieve a desired outcome, free of violence, retribution, or fear' (Klugman et al., 2014, p. xv). Moreover, it is also noted that women's self-agency will not be achieved in isolation, since 'Men, boys, community leaders, and family elders who support gender equality are key allies and stakeholders in changing gender norms' (Klugman et al., 2014, p. 38). Similar to the potentially synergetic relationship between parents and professionals referred to above, increased agency for women can in the same way contribute to the development of capacity in both men and women.

This research has highlighted the necessary contribution of girls' education along with women's empowerment to bring about changes in the lives of women and girls with disabilities, end gender discrimination and support them to become agents of change. Through education girls and women can more actively engage in decision making, build self-confidence and self-esteem, and resist violence. This is also in line with the previous studies that claim that women's empowerment is obtained through formal education and awareness-raising programs (Kabeer, 2005). Awareness and empowerment programs should include girls with disabilities, mothers, grandmothers and mothers-in-laws. Local professionals, social workers and teachers as active agents can play a crucial role in creating awareness and positive images for women in communities, as they occupy an important space by their position in society. They can highlight women's contribution in family and society. Moreover, building the competence of professionals, teachers, school professionals, community people and decision makers is equally important, as they need to integrate such knowledge of women's empowerment into their responsibilities and practices. Under the auspices of the Ministry of Education in Nepal, the Centre of Education and Human Resource Development (CEHRD) and more particularly its Human Resource Division need to take initiatives to formulate policies and develop programs in this area.

As discussed earlier, concerns about the safety of girls with disabilities including violence and the growing number of rape cases has been a burning issue and has contributed to early drop-out of girls with disabilities from schools. To deal with this issue, this research suggests a number of measures such as awareness programs and education for professionals and community members, assurance of strong legal enforcement, effective reproductive and women's health education for teenagers at school level, and preparation of a code of conduct at the community level to ensure the rights of the child recognised by the United Nations, including protection and its effective implementation. Municipalities, local NGOs and clubs can take initiatives for such programs in a cost-efficient manner, such as by using local media (TVs and FM radios).

7.2.5 Inter- and intra-agency cooperation

The findings of this research highlight the issues surrounding fragmentation of services and interventions that are aimed to serve children with disabilities and their families. For example, due to the lack of coordination between educational and medical services, parents are forced to choose one service at the cost of the other. This is because medical and educational interventions in Nepal are operated by two different ministries, whose programs do not interact. Another example of the lack of coordination is that, while education of children with disabilities is the domain of the Ministry of Education, issues such as disability entitlements and distribution of disability cards are handled by the Ministry of Women, Children and Social Welfare. This has prevented children receiving education at locations and times of their convenience, as parents and children with disabilities need to travel to different locations to receive these services. Therefore, the research calls for coordination among different agencies working in the area of disability in Nepal. For this, a coordination committee can be formed representing personnel from different ministries – particularly the Ministry of Health and Population (MoHP), Ministry of Education (MoE) and Ministry of Women, Children and Social Welfare – to issue an information protocol in regard to disability services such as diagnostic help, disability cards, and education or rehabilitation placements. Each municipality then, through their Health and Social Service Unit, should provide the integrated information to parents and families of children with disabilities, so that parents and families can receive all services without so much burden.

This research clearly identifies the scope of potential collaboration between grassroots health workers and education professionals. The existing health and education sectors' policies should aim for a coordinated service structure at the grassroots level to cater for these children and their parents. For example, the training models for health focal persons should include content related to disability. Similarly, the recent initiative of the Ministry of Education to assign a teacher in each school as a health focal person should be linked with local health workers and the proposed 'one nurse per school' program should be linked to address the issues, such as those highlighted in this research, of children with disabilities and their parents.

As mentioned earlier, the community-based rehabilitation (CBR) approach has been recognised as the most important strategic approach for people with disabilities especially in developing nations like Nepal (Kafle, 2010; Prajapati et al., 2015). As CBR approaches essentially entail the involvement of community members in designing and delivering services for children and people with disabilities, this research stresses the importance of and need for strong collaboration between CBR centres and schools for proper identification, intervention and school placement of children with disabilities in rural areas.

Government and non-government agencies' tasks sometimes overlap, for example, when they collect data related to disabilities. However, there are some instances of good collaboration; for example, one school in the research district became able to enrol double the number of students with visual impairment after receiving financial support from an NGO. With that support, the school provided braille education and hostel facilities. However, such collaborative practices are not common. What that implies, however, is both government and non-government organisations should work together for effective impact. Activities such as professional networking, periodical sharing programs, resource mapping and joint annual planning could be useful in this regard.

7.2.6 Fostering inclusion and better school practices

Proper practical support is needed for parents such as those in this research who were not able to place their child in a school. When parents know there is a place for their child, whether in a school or an alternate facility, their minds are eased, and anxiety is reduced. However, as this research has highlighted, despite legally mandatory provisions to protect the rights of children with disabilities to education, provision of adequate placements has fallen short. For example, even when new special needs education classes including inclusive classes (MoE, 2017) and rehabilitation centres were opened not all disabilities were catered for.

Parents in this research viewed education as a powerful tool for their children's future that should be expanded to reach out to a wider range of disadvantaged children. As stressed by various scholars, inclusive practices should not call for a change in children to fit within the existing systems; rather it stresses the transformation of existing systems and structures themselves to fit the needs of children with disabilities (Carrington & Robinson, 2006; Cologon, 2013). Ideally policy makers will have a vision of creating an environment where children's diversities are respected, their needs addressed, and they experience a safe and welcoming atmosphere where inclusivity is every school's regular practice.

While some of the educational professionals from the focus groups in this research advocated full inclusion of students with disabilities, a more realistic position recognises that inclusive education may not work for all children with disabilities, although it is preferable that as far as possible schools do try to accommodate children with disabilities in regular classrooms by making physical and pedagogical conditions appropriate for them, rather than focusing on creating separate facilities. The practical solution to this question may be that the type, severity, and social or environmental contexts of the children with disabilities and their families should determine the most appropriate provision of special needs education (Johansson, 2014). For example, as indicated in Chapter 6, while rehabilitation centres (with a commitment to address education needs and an opportunity to participate in school activities where possible) may be the best option for children with profound impairments for now,[29] special schools can serve the needs of children with severe impairments. It

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[29] Regarding profound disability, there are cases where children cannot hold up their head or need to lie down all the time, due to severe cerebral palsy, for example. I encountered one such case during the field study. With the current level of resources, schools may not be able to cater for these children.

maybe that children with severe disabilities benefit from being with their peers without disabilities for some time while at other times they may require special attention. However, both requirements can be met in the one location. Children with moderate and mild impairment and all children with visual impairment can be served by regular schools after slight modification in the facilities and services. In this way, every child with a disability could have a place either in a school or in a rehabilitation centre.

The research suggests the need to go further however in that, to realise the full potential of each individual child and their parents, interventions should be designed and implemented as per the need of the child. Such interventions should be built on the strengths, capacities, desires, hopes and needs of children with disabilities and their parents (Burrows, 2007; Moore, 2015; Morton & McMenamin, 2011). Although evidence of the success of such interventions focusing on individual children in context is available only from developed countries such as Australia (Burrows, 2007; Moore, 2015), the USA (National Academies of Sciences, Engineering, and Medicine [NASEM], 2016), and New Zealand (Morton & McMenamin, 2011), as well as a few examples from developing countries from Africa (Ngulube, 2016), it is possible that through piloting such interventions and establishing Nepalese examples the potential of such an approach maybe demonstrated as a starting point.

In addition to the above-mentioned discussion points, this research identifies that reform and interventions are needed in several other areas. For example, there is a need for curriculum reform to incorporate practical and vocational skills for students with disabilities. Practical skill-oriented courses appropriate to children's needs could help some children with disabilities move towards independence and help them transit to independent lives, which are aspirations held by their parents. Scholars have emphasised the importance of developing independent living skills to cater for students with disabilities who have an interest in vocational and technical areas (Ashman & Elkins, 1998; Barnes & Mercer, 2005; Hillier, Fish, Cloppert, & Beversdorf, 2007). Given the lack of opportunities for employment in developing countries like Nepal, skill-based courses are even more important to address the needs of children with disabilities who are attracted by such vocational and technical skills. The skill-based curriculum should be appropriately tailored to meet the needs of individuals with different types and severity of disabilities.

Similarly, professional development for teachers and human resources are vital to deliver the special needs curriculum. In Nepal, teaching methods continue to be teacher focused. Previous studies have also noted the importance of teacher preparation and development programs. For example, as Chien and Lee (2013) report, most teachers do not have the capacity to appropriately plan for and teach students with disabilities effectively in mainstream classes in Asian countries, and hence they highlight the need for appropriate training for teachers. Moreover, my research has implications for other training providers, such as training providers for healthcare professionals in Nepal. The training curriculum for local health workers should include disability-related skills, such as identification, early intervention and family supports targeted at children with disabilities and their parents. For example, a basic package of disability service training for all primary health workers working under the Ministry of Health would be of interest of these children and parents. Similarly, courses like disability care training as offered by Technical and Further Education (TAFE) colleges in Australia could be provided in Nepal, either by Nepalese high schools or by the Council for Technical Education and Vocational Training (CTEVT).

Moreover, there is also evidence that short-term courses conducted in other countries for Nepalese teachers, educators and government professionals are effective to link global concepts and local contexts. For example, Beutel, Tangen and Carrington (2019), in their evaluation of one such course organised in Australia for participants from three South Asian countries (Nepal, Sri Lanka and Bangladesh) identified that, ‘for many participants, work habits changed as they applied their learning to include a greater range of diversity in their home countries’ (p. 109) and these researchers also anticipate the long-term sustainability of the program. Although no such courses have been organised in recent years in Australia, my research recognises the impact of such programs to date and therefore, strongly suggests seeking opportunities for such short courses in the future also.

In addition, adequate resource allocation to meet the growing need for infrastructure improvement or disability-friendly transportation systems to ensure that children with disabilities have physical access to schools and other facilities should also be an area for national and local government attention. Similarly, policies and institutional reform to prioritise employment opportunities for parents of children with disabilities may assist in alleviating some of the financial burdens experienced by these families.

Moreover, as a relational study, this research appreciates and values different perspectives coming from every corner. It sees the roles of both central government authorities and local institutions as very important in the effective provision of resources and infrastructure to support successful educational options for children living with disabilities and hence calls for a balanced approach, where both central agencies and local bodies play significant roles. The central government, including policies, processes and institutions, cannot be the antithesis of local functions, because strong central agencies can facilitate and support local institutions and services to bring about changes. For this, the central agencies can play important roles in enacting conducive policies, allocating enough resources, educating and empowering people, and disseminating the successful practices of one community to others, and thereby encourage schools and professionals by providing clear examples and processes for engaging with parents and communities.

Overall, the findings from this research indicate that it is not easy to achieve such changes quickly and so we should not expect changes to occur immediately, particularly because changing deeply rooted values and norms is difficult and complex. However, we can lobby for visible steps towards reform supported by being mindful of the outcomes generated from this research and prioritising them for action. Initial actions may include creating a steering committee of key officials from relevant ministries to address more effective coordination of health and education disability-related services. At the local level the establishment of a dedicated unit in each municipality office to support the needs of parents and children with disabilities is also recommended. In essence, action should be prioritised at the local level as this will have more direct and powerful influence on families' quality of life, but local government initiatives must be well supported by national government policies.

A number of recommendations and practical strategies for improved parental engagement and successful life experiences and outcomes for children with disabilities are integrated in the above discussion. Key suggested recommendations and strategies are compiled and once again presented below (in dot points and also depicted in Figure 7.1) to highlight their importance so that government, policy makers, training institutions, local professionals including head teachers, teachers and other service providers can prioritise these strategies and extend their support to children with disabilities and their parents and families:

- Central level policy makers as well as local health and education professionals, who have early contact with families, need to recognise the usefulness of traditional folk wisdom along with modern scientific knowledge so that they can create a bridge to connect old and new worlds and meet families where they are.
- All levels of governments need to expand their existing services to cover all people with disabilities and they also need to explore options to initiate new schemes such as health insurance targeting people with disabilities and their families.
- Central level policy makers need to initiate an operational mechanism to coordinate the disability-related services provided by different government and non-government agencies.

- Training institutions need to design and implement appropriate capacity development programs around disability for parents, teachers, *aayas*, health workers, *sudenis* (traditional birth attendants), faith healers and social workers.
- Municipalities, local NGOs and clubs need to provide orientation sessions for parents, community members and frontline service providers on different aspects of disability, legal provisions and measures, children's rights, women's health and so on.
- Policy makers, professionals and community members need to recognise different social and cultural elements as influential in creating exclusion and hardship in the lives of persons with disabilities and their families and try their best to minimise the effects of such elements in their practices.
- Government and local schools need to provide appropriate training and support to *aayas* working in integrated schools and address the grievances related to their compensation.
- Village municipalities in coordination with the Ministry of Women, Children and Social Welfare need to establish more rehabilitation services to cater for children with profound disabilities, so that all children can have a place in rehabilitation centres or schools.
- Rehabilitation services need to include psychological and emotional support for parents including counselling, yoga or meditation so that they feel their needs are being addressed.
- Professionals need to have at their disposal up-to-date information about services that parents and their children need, such as child-specific information, assessment and identification, social support, transition planning, respite care, counselling and so on.
- School leadership and staff need to involve parents in decision making in school affairs, timetables, dress codes and school activities, and regularly seek input from parents when evaluating schools' activities.
- Schools need to prioritise addressing parents' needs for greater communication by proactive communication through newsletters, reports and phone calls, and encourage meetings at times that fit with parents' availability.
- Teachers need to invite parents to support classroom organisation/decorations and participate in extracurricular activities.
- Teachers need to visit homes to inform parents about local services and resources which are available for these parents and their children with disabilities.

- Schools need to facilitate regular parent-to-parent meetings for parents of children with disabilities so that they feel that they are not alone in raising their child.
- School leaders need to draw on the needs, hopes, strengths and resources of parents, families and teachers and reflect them in schools' planning and programs.

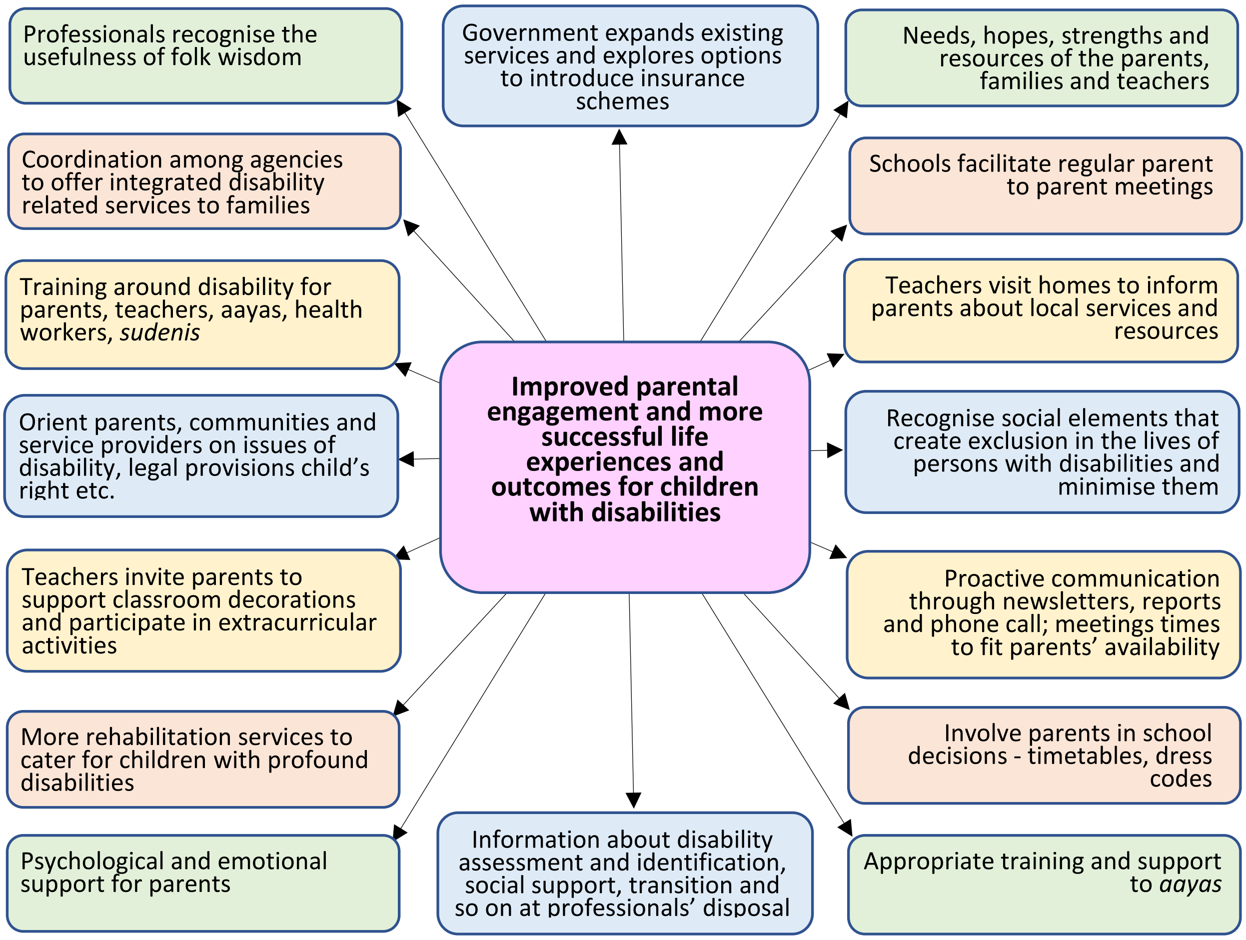

Figure 7.1: Key suggested recommendations and practical strategies

7.3 Future research

The participants in this research were the parents of children with disabilities, education professionals and community members. Since this research did not include the voices of children with disabilities and experiences of medical professionals, future research could usefully draw on their voices and experiences to complement this study and provide further information and guidance about parent engagement in the schooling of their children with disabilities and ways to link health and education. Similarly, as this research demonstrates that parents' experiences differ according to the type and severity of their children's disabilities, it may be useful to explore how to include the voices of parents of children with diverse needs not considered in this research, such as autism.

The need for greater collaboration within different government departments and between public and non-public institutions was clearly demonstrated by this research. Given the tendency of every government department to extend their own scope and services and enjoy their own empire, the realisation of proper collaboration could be difficult. Future research could explore many areas of potential collaboration including between government departments, and between government and non-government agencies. An outcome of this research could be a pilot study focusing on the design and implementation of a parent–school engagement program involving the collaboration of education and health services at the local level.

This research has found that both parents and professionals view parental engagement in schooling as a good thing. While they paid lip service to the concept in theory, this research has demonstrated that parental engagement is not occurring in practice and further research is needed into the slippage between theory and practice in education, which is also manifested in other service areas such as health.

In addition, future ethnographic studies of parents' lives over a prolonged period as their children with disabilities mature or phenomenological approaches to researching parents' lived experiences would give additional insight into what contributes to building parents' resilience, and what interventions would actually support them in living with their children's disabilities.

Finally, this research has identified a gap between local wisdom and scientific knowledge in relation to understanding disability including cure and treatment. Some believe these worldviews are not reconcilable; however, this research emphasises that both scientific and local folk knowledge are important to understand the subtlety of parental concerns regarding disability issues. Future research is needed to explore how to harmonise these two worlds (that is science and traditions, North and South, West and East, reason and religion) in order to draw on and integrate local folk wisdom and state-sanctioned scientific knowledge.

7.4 Trustworthiness of the research

Essential contributors to the trustworthiness of this research involved paying attention throughout to what relational researchers Finlay and Evans (2009, p. 61) describe as 'rigour, relevance, resonance and reflexivity'. They see rigour as being how the overall study is managed and worked through and to what extent research findings are based on evidence. Relevance, to them, is the applicability and contribution of the research and how the methods used were empowering to participants. Similarly, resonance refers to the extent to which the researcher is touched by the findings, how readers enter the research report emotionally and how 'artistically' the findings are presented. Finally, reflexivity is the researcher's openness and self-awareness about the research process and outcomes and how the researcher's subjectivity impacted on the study.

Transparency within the research process was a major aim and influenced my actions in the choice of methodology, research site, participants, and analysis and interpretation techniques. I believe transparency is evident throughout the thesis which serves to ensure the trustworthiness of the research. The inclusion of multiple sources of data, prolonged engagement in the field, empowering methods used to gather data, data presentation in the form of descriptive and evocative portrayals of participants and contexts as well as in themes, peer review, ongoing researcher reflexivity reflected in *a priori*, *in situ* and *posteriori* subjective reflections, and finally, a follow-up visit to the site all provide evidence of transparency and subsequent trustworthiness.

Multiple sources in terms of both types of data as well as research participants were used to gather in-depth data for this research. Types of data obtained were informal interview conversations and interactive vignette-based focus group discussions, which were supplemented by reading of relevant documents and a research journal. These data were collected from a number of participants representing parents of children with disabilities, education professionals comprising head teachers, mainstream and resource teachers, community members, and local level government officials from education and local *palikas* (councils). The approaches employed to elicit rich data to report in this research were designed with a view to engage and empower participants, by flexibly tailoring the methods to their circumstances, and by being open to meet them for conversations at the places and times of their choice, such as in their homes, in schools and in local tea shops. They were approached with interest, listened to carefully, their language was spoken to draw them out and they were encouraged to actively engage in the conversations. In addition, the authentic and interactive vignettes drawn from the parents' real stories were used for the focus group discussions to keep professionals and community members grounded in everyday realities. A significant amount of time – three months – was spent in the field, with part of this time used to build rapport with the participants before gathering the data, in order to establishing trusting relationships and connections with the aim of eliciting more authentic data.

Descriptive and evocative forms of writing including case-focused narratives or portrayals drawing on participants' own words and contexts along with the feelings and emotions of both participants and myself were used to assist readers to connect emotionally with the findings and connect with participants' authentic experiences, understandings and voices. Similarly, thematic narratives as well as interpretations of findings were also supplemented by participants' quotations and contextual information to assist readers to determine the degree of relevance of the findings to their contexts. In addition, although relational or narrative research is a textual undertaking, the thesis included several figures and tables, including the interactive story map in Chapter 6, to present the data and findings in an attractive way with a view to make the thesis reader friendly, thereby enhancing the 'resonance' of the research (Finlay & Evans, 2009; Lapum et al., 2015).

Peer-review was an important contributor to the trustworthiness of this research. During the course of this study I received valuable ongoing feedback from group supervision with fellow doctoral students. Their questions and comments during our reading circles and discussions informed my reflections on the implications and relevance of this research and are reflected in our group journal articles (Bissaker et al., 2019; Henderson et al., 2016). I also presented preliminary findings from this research at various conferences and meetings with a view to seek feedback from colleagues and critical friends. A list of conferences and meetings attended for this purpose is listed in Appendix I.

Ongoing researcher reflexivity throughout this research provided another data source and opportunity for further reliability. I articulated my feelings, emotions, decisions, observations, reflections and speculations in a researcher diary throughout the entire field work, which helped me to retrieve reflections when writing different sections of this thesis. In addition, as indicated in Chapter 1, I present my reflexive accounts at different stages, an *a priori* reflection at the beginning of the research, an *in situ* reflection in the midst of the research, and finally a *posteriori* reflection, as an overall reflection, towards the conclusion of this research in this chapter. Many impressions incorporated in the *in situ* and *posteriori* reflections are drawn from examples in my researcher diary.

In order to check if my interpretations were correct, following transcription and initial analysis, a follow-up visit to the field was undertaken to share the key themes and initial findings of this research to a small group of parents and professionals. This follow-up process is important in relational research because, according to Finlay and Evans (2009), 'The process of tying up the research with co-researchers usually involves some sort of debrief towards closure of the research relationship' (p. 170). On this visit, in early January 2019, two years after my first field work, I was accompanied by my principal supervisor, Dr Leigh Burrows.[30] In this follow-up visit, participants were encouraged to provide further input, amendment or corrections. The comments and feedback

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[30] Gary Whaite, Leigh's husband, also accompanied us on this follow-up field visit and contributed to our discussions with the participants.

received at this stage were incorporated in the analysis. During this visit we were able to meet in person with two key parent participants and their families and one key focus group. A brief summary of three events from the follow-up visit is presented in Appendix J. My supervisor's engagement with the participants including observation of research sites has increased the authenticity of the data collection process. Her visit to the site was a form of member checking in which she was able to corroborate the findings by going to the participants' homes, meeting them, participating in conversations and gaining experiences of the research contexts. On her return, she went through the findings including the in-depth portrayals of the four participants presented in Chapter 4 and the themes-based narratives in Chapter 5 with fresh eyes and made suggestions to reflect the contexts of the sites. This visit therefore was not only important to reinforce the relational aspect of the research through enhancing the supervisor–student relationships as well as researcher–co-researchers relationships, but also to ensure the validity and thereby the quality of the research.

7.5 Research limitations, and efforts to mitigate them

The research has limitations in that it has not captured the voices of other possible participants, such as children or students with disabilities and medical professionals. However, a wide variety of participants within both the parents' group (such as parents, grandparents, a brother and a brother-in-law) and professionals' group (such as regular and resource teachers, head teachers and assistant head teachers, members of school management committees and parent–teacher associations, and local government officials) were willing and valued participants. Another limitation is, due to the relational nature of this research I wished to interview only those participants who chose to volunteer and those referred by them. As such, only the more active and enthusiastic participants are likely to have been represented in the research, while missing the voices of those who were silent and did not come forward. However, I tried to mitigate this limitation by including accounts of other examples of children and families made by participants whose voices would not otherwise have been heard.

Moreover, there might be questions about to what extent the voices of female participants could be elicited by a male researcher asking about their experiences as women and mothers. As multifaceted issues regarding gender roles have emerged, female participants have offered authentic accounts of their stories and experiences in this research. While every care was taken in this relational research to be respectful, to listen and to give a voice to all participants, there remains a chance that a female researcher might have obtained even more information from the female participants in the research.

7.6 *Posteriori* reflection: On coming full circle

The reflective accounts presented in different chapters of this thesis represent an effort to honestly report the feelings, emotions, biases and insights about what was going on with myself as a researcher prior to, during and at the close of the research. Through this research, I wanted to elicit nuanced data in order to explore the subjective experiences and perspectives of parents of children with disabilities and relevant education professionals. For me, such nuanced data needed to be based in an understanding and respect for culture and context. For this, I found a relational research methodology was attuned with this aim. It also helped me to work with hard-to-reach people in naturalistic settings without imposing any artificiality in their day-to-day life. I was able to explore and bring to the front the concerns and voices of those who have been ignored in the research realm in Nepal. I felt that other approaches might not illuminate people's conceptions, perceptions, feelings, values, attitudes and intelligence. Initially, as a bureaucrat working at the central government level and as a student undertaking a PhD from a foreign university, I felt it might be difficult for me to gain the confidence of the participants and communities; however, a relational research approach proved to be the right choice to overcome such barriers and to establish close linkages with the community.

While relational inquiry assisted me in the research process, particularly during the field work, the narrative approach also became instrumental to presenting and analysing those voices in more comprehensive ways. The narrative approach further allowed me to connect back to the participants through their experiences, stories and insights during the whole process of data presentation and analysis, and thus the approach to analysis also aligned with the relational orientation of this research. Through the narrative approach to data analysis, I became able to uncover the meanings participants' voices were carrying for a wider audience or the messages their stories conveyed for different constituencies including individuals, families, schools and local institutions.

Conducting this research helped me recognise that knowledge is essentially relational in nature and open to further interpretations and scrutiny, so that I could also incorporate various ideas put forward by my supervisors and my peers as critical friends during the research journey. The contributions made by my participants as co-researchers, my supervisors and peers further reinforced my belief about the relational nature of reality that 'I' cannot stand alone, that the existence of 'I' is relational, and that 'I' and other are inseparable. By now I even become able to conclude that, for a relational researcher, imagining the existence of a 'self' without 'other' is problematic, questionable and even impossible.

This relational research has not only enabled me to access parents, professionals and community members in remote rural areas of Nepal for the purpose of data elicitation, it has also provided space to reconnect with them. In the past, as a school supervisor at different district offices, I worked with parents on some occasions such as when supporting schools to develop their school improvement plans. That allowed me to appreciate the roles of parents in the schooling of their children. During this time, the field of parental engagement became my interest and passion. However, in recent *years, when I came to the central education department, I was not required to work with parents, teachers, community members and local level professionals on a day-to-day basis. I felt like I was missing the interactions with these people at the local level. Through this research I became able to re-establish a link with parents and local communities again.*

Moreover, during the entire research process, I was aware that I should try to be mindful and transparent about my preconceptions to bring particular knowledge and strengths to this research and also equally aware that it is very difficult to do this entirely due to conditioned cultural and social disposition, experiences and biases. However, I tried to step back as far as possible to allow a space for new knowledge to arise from this research.

I started this research with an intent to focus more on exploring parents' experience of educating their children with disabilities and their engagement in schooling of their children with disabilities. Being an employee of the Ministry of Education, I initially did not realise that parents had significant medical concerns. When I went into the field, and listened to parents, I became aware that their healthcare concerns were paramount, especially during the early years of their children's lives, which was a significant new learning for me.

Furthermore, previously I did not realise the importance of viewing disabilities through different lenses. I was not even quite aware of the subtleties of different perspectives before undertaking the literature review for this research. This could possibly be due to my background coming from mainstream education and my focus on looking at the issue from a mainstream point of view. For example, the social perspective of disability has gained momentum, but I was not aware of usefulness of this perspective in understanding disability from a rights-based/empowerment-based perspective. As these different lenses view disability differently and imply different interventions, I now find that knowledge about these perspectives is beneficial for all educational professionals and much needed. They help determine different educational interventions for children with disabilities, because the interventions we tend to devise for these children are likely to vary according to the perspective we take.

Now that this research is completed, I feel excited about returning to Nepal to share this new knowledge with colleagues and communities with the hope that they will join me on a new journey. I want to initiate dialogue through writing and presenting with the aim of beginning to integrate local folk wisdom and scientific knowledge. I will invite health professionals and policy makers as well as colleagues in education to work together on a new project that could support children with disabilities and their parents in a meaningful way and that could tap into the potential of parents of children with disabilities and other local resources.

7.7 Conclusion

This research has centred on eliciting the experiences and perspectives of parents, local education professionals and community members on the topic of parents' engagement in the schooling of their children with disabilities. The use of empowering and engaging approaches to elicit previously hidden voices has produced new findings about the potential of parents to contribute meaningfully to the schooling of their children. Thus, it is not just what has been found that is important but how it was found. Since relational approaches to research are very scant in Nepal, as many scholars tend to be drawn to a more positivist orientation, this research also contributes to the development of more diverse methodological options for research in Nepal.

Both parents and education professionals including community members are highly aware of the importance of education for children with disabilities and the role of parental engagement in schooling for the success of these children. In the pursuit of better schooling, parents are ready to accept available resources, want to use them in the best possible ways and are willing to contribute with the expertise, knowledge and resources at their disposal. However, during their journey of caring for their children with disabilities and attempting to connect with their children's schooling, parents encounter several challenges, including differential understandings about disability between professionals and themselves, different priorities of government staff and themselves, stigma and humiliation, unaffordability of services and unequal relationships.

However, school settings play only a partial role in the education of children with disabilities, and input from parents would significantly assist professionals to design programs and help address the needs of parents and their children with disabilities. Nonetheless, the research suggests that all parents – whether educated or uneducated, privileged or unprivileged, whether their child has a disability or not possess authentic knowledge about children with disabilities, their needs and their education. It is possible, as has been shown by this research, that parents can contribute greatly to professionals' efforts by working together with them as equal partners, yet with different roles.

However, parents at the same time are also concerned about their children's healthcare needs. Educational professionals and policy makers in Nepal need to appreciate that parents' medical and education concerns and needs are intricately linked. They need to know about the medical concerns of parents of children with disabilities in order to effectively respond to their educational needs. Currently efforts to address the needs of parents and their children are not sufficient. While healthcare needs of children with disabilities are a major priority for parents, education professionals have limited understanding about this need. As the health and education services are operating in isolation, parents are compelled to choose one at the cost of the other. This suggests that merely opening schools for children with disabilities is not enough to address the education needs of these children; rather the research underscores the urgent need to focus on their healthcare needs along with their education needs. As there are limited opportunities to sufficiently engage professionals with these issues in their work environment or training programs or in the legal frameworks they encounter, this research suggests appropriate training and awareness programs targeting professionals. Similarly, there is a need for new understandings about parents' cycles of grief in order to devise appropriate support and timely interventions for them.

Overall, researchers and education and health professionals working with children with disabilities and their parents would do well to focus at a more individual level. There is a need to appreciate parents' wisdom and resources regarding the health and education of their children and to begin creating welcoming community environments where local folk wisdom and scientific knowledge can be shared. The research concludes that greater collaboration between parents and local level professionals will provide an important foundation and promise for a better future for marginalised families in Nepal.

APPENDICES
Appendix A: Glossary

Glossary Part I: List of acronyms

CBR	Community-Based Rehabilitation
CBS	Central Bureau of Statistics
CEHRD	Centre for Education and Human Resource Development
CERID	Centre for Educational Research Innovation and Development
CRPD	Convention on the Rights of Persons with Disabilities
DoE	Department of Education
ECDC	Eden Centre for Disabled Children
EFA	Education for All
FAO	Food and Agriculture Organisation
FEDC	Family Empowerment and Disability Council
GoN	Government of Nepal
HDI	Human Development Index
IEP	Individual Education Plan
MFSC	Ministry of Forest and Soil Conservation
MoE	Ministry of Education
MoES	Ministry of Education and Sports
MoF	Ministry of Finance
MPhil	Master’s in Philosophy
NCCAH	National Collaborating Centre for Aboriginal Health
NESP	National Education System Plan
NGO	Non-Governmental Organisation
NHRC	National Human Rights Commission
NLC	Nepal Law Commission
NPC	National Planning Commission
PhD	Doctor of Philosophy
PTA	Parent–Teacher Association
SCA	Secretariat of Constitution Assembly
SMC	School Management Committee
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children’s Fund
VSO	Voluntary Service Overseas
WB	World Bank
WHO	World Health Organization

Glossary Part II: Definition of the key terms

Children with disabilities:	Children of school age (0–18 years) with disabilities are taken as children with disabilities in this research. Although the different terms 'children with a disability', 'children with disabilities', 'children with disability' or 'children with special needs' refer to the same meaning, I tend to use the term 'children with disabilities' in this research as any child with a disability is prone to have multiple disabilities. In addition, terms that integrate disability with persons' identity, such as 'a disabled person' are strictly avoided. Instead, terms such as 'persons with disabilities' are used as they enable persons to be considered first and see the disability as just one aspect of their identity (Todd, 2007, p. 19).
Disability:	'The condition of difficulty in carrying out daily activities normally and in taking part in social life due to problems in parts of the body and the physical system as well as obstacles created by physical, social, cultural environment and by communication' (GoN, 2007, p. 2).
Folk wisdom:	Indigenous local knowledge rooted in people's cultures and years of experiences, which has wide applications to social, political and religious life and links both the cultural and natural spheres (Bruun & Kalland, 2014, see p. 7).
Guardian:	According to the Education Act of Nepal, guardians are 'those persons who are recorded as the guardians of the children at school registers' (NLC, 2010, p. 5). The term also includes any other adult, grand- or step- parents, uncles, aunts or carers, brothers and sisters, who are responsible for parenting the child.
Impairment:	'Any loss or abnormality of psychological, physiological or anatomical structure or function' (World Health Organisation, 2001, p. 1). Impairments can be categorised into three main types: physical (body), sensory (ear, eye, or lip/tongue/speech), and intellectual (mind).
Parent:	A person's father or mother, or persons who have been involved in the raising of a child including non-biological, non-adoptive parents.
Parental engagement:	'Parental engagement involves partnerships between parents and schools, that children's learning is a responsibility shared by both parties, and that parents and teachers play different but important roles in children's learning' (Fox & Olsen, 2014, p. 20).
Professionals:	The term 'professionals' is used in this research to refer to: teachers (including resource teachers who teach special needs children) and head teachers; community members representing school management committees and parent–teacher associations; and government local officials such as school supervisors/resource persons (staff of district education office responsible for schools' supervision and teacher support), and representatives from *palikas* (local government administrative service centres headed by a political leader elected periodically for a five-year term).

Reflexivity:	Reflection, as ongoing self-awareness, is a dynamic process in research, which illuminates the researcher’s position, decisions taken, and choices made by the researcher at every stage of the research process including data elicitation, analysis and interpretation (Finlay & Evans, 2009; Kinyany-Schlachter, 2017).
Special needs education:	In this research, the term ‘special needs education’ is used to refer collectively to all types of educational provision targeted to educate children with disabilities in Nepal: namely, segregated schools (special schools that are targeted to students with a particular type of disability); integrated schools (run within a mainstream school but in a segregated classroom); and inclusive schools (that are envisioned in policy documents).

Glossary Part III: Nepali words/phrases used with their closest meanings and interpretations

Aaya (aayas):	An *aaya* or caretaker is a member of the school staff in integrated schools in Nepal; generally, a female hired on a temporary basis by the school to take care of the children with disabilities living in the hostels.
Afno-manchhe:	Own-people. An *afno-manchhe* is a culture of favouritism based on personal relationship, that is knowing the people who provide a service makes a remarkable difference in obtaining prompt services; otherwise, nobody listens.
Atithi devo bhava:	A guest is like a god.
Bali*:*	Making vows and sacrificing animals to please deities and to fulfil vows.
Bhat-khwai:	One of 16 impotant Hindu rituals when a child is fed with rice or solid food for the first time when he/she becomes 6 months old
Dalit (Dalits):	*Dalits* are the so-called lowest group in the traditional caste-based hierarchy: 'Dalits are those communities who, by virtue of atrocities of caste-based discrimination and untouchability, are most backward in social, economic, educational, political and religious fields, and are deprived of human dignity and social justice' (Sunar et al., 2015, p. 6).
Dhami (dhamis):	Faith healers
Dhami-jhankris:	Traditional healing practice in which the practitioner uses drums and sticks to remove evil spirits from a sick person's body
Dharma:	Duties suggested to be performed by humans in accordance with the law of nature
Gaunpalikas:	Village councils, the lowest level of government institute to deliver public services. Palikas, previously called village development committees, are local government administrative service centres headed by a political leader elected periodically for a five-year term.
Gosai Acchat*:*	The practice of the southern Terai region in which a person prays to a god or goddess, and invites them to enter his/her soul so that he/she will become able to tell the past, present and future of a sick person
Grahadasha:	Good and bad aspects of the planets determined by their positions at the time of birth, which accords with one's horoscope
Guru (feminine form guruma):	Teacher. In general use also includes religious preachers and orators
Jadibuti (jadibutis):	Roots and herbs, traditional medicines

Janajati:	Indigenous nationalities
Jantarmantar:	Traditional healing practice in which practitioners wear a healing amulet
Jat/jati:	Caste/ethnicity. The caste system refers to a complex structure of social divisions which plays an enormous role in the lives of Nepalese, and is an ancient traditional practice in Nepal. The caste system, traditionally, is a division of people based on their occupations and professions, priests & teachers (Brahmins), warriors & rulers (Kshatriyas), farmers, traders & merchants (Vaishyas), and labourers (Shudras) (Hofer, 1979/2004; Bhattachan, 2003; Pandey, 2005). People involved in dirty jobs, such as cleaning, were placed below these four castes and considered ‘untouchables’; however, now they are included in the fourth group. While all castes are found in Terai, only three (with the exception of Vaishya) are found in the hill region and no caste system prevails in the mountain region (Bhattachan, 2003). Another interpretation of the caste system holds that each caste is a representation of a different level of purity or pollution, Brahmins being the highest/holiest caste and Shudras being the most impure ones (Paudel, 2018).
Jhankri (jhankris):	Shamanistic treatments
Jharphuk or phukphak jharne:	Blowing of breath into the body
Jyotish:	Palmist astrologers who examine the palm or horoscope to explain the problem and then suggest different rituals to perform
Karma:	*Karma* is a law of cause and effect, which is reflected in the maxim ‘as you sow, so you reap’. This means that it is believed that everyone is bound to bear the result of his/her actions. The wheel of *karma* (result of an action) can even transcend physical lives of the soul (Sarvapriyananda, 2018; see also Bilimoria, 2007; Shree, 2013) and yield the fruitions of one’s action in one’s future lives.
Nwaran	Name giving ritual performed for a baby on the ninth day after his/her birth
Pakhe:	A common Nepali slang term for an ignorant, uncivilised person, who does not know the modern world or contemporary events. Literally *pakhe* means a person who lives in a hilly area. However, it is offensive to call someone a *pakhe*.
Pandhero:	Common watering place, well or stream.
Puja:	Worshipping particularly the deities, including the practice in Nepal of offering prayers and performing rituals to cure people. Puja is performed by the respective priests of different religious groups – lama for Buddhists, pandit/pujari for Hindus and gubaju for Newars.
Punya karma:	An act of saintly, sacred, just or righteous action that could lead people to salvation
Saatu:	Flour made of roasted corn or barley

Sabhya:	Civilised persons/societies, which are often highly valued, and respected as significant and knowledgeable.
Sanskriti (Nepali sanskriti):	Culture (Nepali cuture). Nepali cultures are rich and multi-dimensional because of the vastly diverse nature of Nepali society, and therefore it is also difficult to describe a representative ‘culture’. However, the geography between Tibet (China) and India, centuries-long religious practices, mainly shaped by two predominant religions, Hinduism and Buddhism, people’s daily lives and chores shaped by the snowy mountains and Himalayas in the north, by rocky hills and numerous rivers in the middle and by fertile plains, known as Terai, in the south, people’s collective behaviours, and the male- and caste-dominated practices of the hill and Terai regions are what define the culture(s) of Nepal. This multidimensional influence over Nepali cultures is manifested in every aspect of daily lives, including foods, costumes, rituals, festivals, artefacts, music, dance, art, craft, folklore, folktales, languages, literature and so on. Patriarchal culture, for example, manifests in the form of the suppression of women; however, they are highly regarded as mothers (Davis, 2014). Many people do not compromise in the practice of rituals and celebration of festivals, despite their unaffordability and considerable time commitment. Collective culture manifests in the form of the joint or compound family. People combine their assets in the family to ensure each member feels secure, friends and relatives come forward to help others in need and so on. Belief in fate and destiny and superstitious practices that are not founded in scientific reasoning also forms a part of Nepali cultures (Bista, 1991; Wasti, Randall, Simkhada, & Van Teijlingen, 2011). One’s appearance is not as important as one’s age, profession, education and family background, because these considerations determine people’s status and reputation. Accordingly, they obtain respect from others. To locate one’s position based on one’s caste is still a part of Nepali culture. Caste-based norms continue to be a dominant aspect of social stratification in Nepal, although the caste system was banned in 1962 (Paudel, 2018; Dawadi, 2019).
Sarsallah:	Nepali word for mutual advice, counselling, consultation; unlike other types of advice, *sarsallah* can occur between persons of the same status.
Shraddha:	A ritual in the Hindu religion performed each year in honour of dead family members including ancestors, in which family members offer water, balls of rice pudding and so on to their dead ancestors
***Sudeni (sudenis)**:*	A traditional birth attendant, especially female who helps rural mothers during deliveries
Terai:	Southern fertile plain lowland of Nepal, one of three geographical belts of Nepal that spread from east to west. The other two are the snowy mountains and Himalayas in the north and the rocky hills with numerous rivers in the middle.
Thulaa badaa jaanne sunne:	They who are at the top know best, a part of Nepali culture
Thulo manchhe:	A big person. Any child aspires to be a big person in the future with a big name, fame and social status.

Appendix B: Introduction letter

Flinders
UNIVERSITY

Dr. Leigh Burrows
Senior Lecturer
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GPO Box 2100, Adelaide SA 5001
Tel: +61 8 8201 3022; email: leigh.burrows@flinders.edu.au
CRICOS Provider No 00114A

INTRODUCTION LETTER*

(For parents, interview participants)

Dear Parents

Mr. Kamal PokhrelSharma is a doctoral student in the School of Education at Flinders University. He is undertaking a research project leading to a production of a thesis or other publications on the subject of experiences and engagement of parents of children with a disability in Nepal.

I would be grateful if you assist him with this project, by consenting to participate in a conversation lasting between one to one and half hours. You would be entirely free to discontinue your participation at any time or to decline to answer particular questions that you do not want to answer. Confidentiality will strictly be maintained, and no participants will be individually identifiable in the resulting thesis and other publications.

The researcher will seek your consent, on the attached form, to make an audio recording of interview, to use the recording or a transcription in preparing the thesis, report or other publications. Be assured that the recording will be treated in the strictest confidence on condition that your name and identity will not be revealed, and that recording will not be made available to any other person. He will summarize the results from the research project after transcribing the discussion and make it available to you, if you want to see them.

Any queries you may have concerning this project should be directed to me at the address above or by telephone +61 8 8201 3022 or by email **LEIGH.BURROWS@FLINDERS.EDU.AU**. Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

Yours Sincerely
……….
Dr. Leigh Burrows
Senior Lecturer, School of Education

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inspiring
achievement

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*Similar type of Introduction letters were provided to the Head teachers/Teachers/Community members of related three schools and government's local officers.

Appendix B (Nepali translation)

परिशिष्ट ख : अनुसन्धानसम्बन्धी परिचयपत्र

डा. लिइ बरोज
वरिष्ठ प्राध्यापक
शिक्षा, मानविकी तथा कानुन विभाग (रुम नं. ५.५७)
फिलन्डर्स विश्वविद्यालय, बेडफोर्ड पार्क साउथ अष्ट्रेलिया, ५०४२
जिपिओ बक्स २१००, एडिलेड, ५००१
फोन. +६१ ८८२०१ ३०२२, इमेल. leigh.burrows@flinders.edu.au
CRICOS Provider No. 00114A

अनुसन्धानसम्बन्धी परिचयपत्र

(अन्तरवार्ताका सहभागी अभिभावकज्यूहरुका लागि)

श्री अभिभावक ज्यू

प्रस्तुत विषयमा श्री कमल पोखेल शर्मा यस फिलन्डर्स विश्वविद्यालय, स्कूल अफ एजुकेशन, एडिलेड, दक्षिण अष्ट्रेलियामा विद्यावारिधिको विद्यार्थी हुनुहुन्छ। निजले शोधपत्र तथा अन्य लेख रचना प्रकाशन समेत गर्ने प्रयोजनका लागि **नेपालमा अपाङ्गता भएका बालबालिकाको अभिभावकहरूको सहभागिता सम्बन्धमा स्वयम अभिभावक तथा शिक्षा पेशामा संलग्न व्यक्तिहरूको अनुभव र बुझाइ विषयको** अनुसन्धान कार्य अन्तरगत हाल सूचना संकलन गर्ने क्रममा हुनुहुन्छ।

उक्त अनुसन्धान कार्यका लागि एक देखि डेढ घण्टासम्म लाग्ने अन्तरवार्ता कार्यक्रममा संलग्न हुन मन्जुरी दिई उक्त छलफल कार्यमा आफ्ना धारणा राखि दिनु भई निजलाई सहयोग गर्नु भएमा म आभारी हुनेछु। तपाई छलफल कार्यक्रमको जुनसुकै समयमा असहभागिता जनाउन, कुनै खास प्रश्नको उत्तर नदिन पुरै स्वतन्त्रता हुनुहुन्छ भन्ने कुरा पनि आश्वस्त पार्न चाहन्छु। अनुसन्धानका क्रममा यहाँले व्यक्त गर्नुभएका विचारहरू हरतरहले गोप्य रहने छन्। यस सन्दर्भमा शोधपत्र लगायतका लेख रचना प्रकाशन गर्दा यहाँको नाम उल्लेख नगरिने कुरामा विश्वस्त गराउन चाहन्छु।

नाम परिवर्तन गरी यहाँका विचारहरू प्रकाशन गर्न भने यसले बाधा पुऱ्याउने छैन। अनुसन्धानकर्ता कमल पोखेल शर्मालाई छलफलमा प्राप्त सूचना तथा तथ्याङ्क विश्लेषणका कार्यलाई सहज तुल्याउन तपाईसंग हुने छलफल अडियो रेकर्डिङ गर्नुपर्ने हुँदा संलग्न फारम बमोजिम यहाँको मन्जुरीनामाका लागि अनुरोध गर्नुहुनेछ। यहाँको नाम र परिचय कुनै पनि प्रकारले नखुल्ने वा गोप्य रहने र रेकर्ड गरिएको सामग्री अन्य कुनै पनि व्यक्तिलाई नदिइने शर्त उल्लेख गरिएको मन्जुरीनामा पत्रमा हस्ताक्षर गरी आफ्ना विचार तथा धारणा रेकर्ड गर्ने स्वीकृति दिनु हुनका लागि पनि अनुरोध गर्दछु। छलफलहरुको लिप्यान्तरण पछि यस अनुसन्धान कार्यबाट प्राप्त परिणामको तपाईले हेर्न चाहेको खण्डमा निजले उपलब्ध गराउनु हुनेछ।

यस अनुसन्धानका सम्बन्धमा थप जानकारी आवश्यक परेमा यस पत्रको शीर्ष भागमा उल्लिखित ठेगानामा वा टेलिफोन नं. +६१ ८८२०१ ३०२२ वा मेरो इमेल LEIGH.BURROWS@FLINDERS.EDU.AU मा सम्पर्क गर्न सक्नु हुने पनि जानकारी गराउँदछु। यो जानकारी पत्र अध्ययन गर्न समय दिनु भएकोमा तपाईलाई धन्यवाद छ र यस सोधकार्यमा संलग्न भइ दिनु हुन गरिएको यस आमन्त्रणलाई यहाँले स्वीकार गर्नुहुने छ हामीलाई आशा छ।

भवदीय

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डा. लिइ बरोज
वरिष्ठ प्राध्यापक, शिक्षा शास्त्र स्कूल

inspiring achievement

Note: Preeti font is used for the typing of these materials translated into Nepali; Preeti font may be available from this link. https://download.com.np/index.php?option=xkx6MYC9Plxn1kFlPjfu5IMwegPILTeROMdQgdOqPcg&file=ERYHa9JyhvZcMUzE1CwyeNllZydY6K2GkuQLFXnqifU&fbclid=IwAR1fXhGuFS_9XjTyoI7T-4_ntiuIlI8Zchiqz00kvXi-_uN3uGI8NKl0dSo

Appendix C: Information sheet

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CRICOS Provider No 00114A

Information Sheet*

For parents of children with disabilities currently enrolled in school

Research Title: An exploration of experiences and perceptions of parents of children with a disability and education professionals regarding parental engagement with schools in a western district of Nepal: Implications for future policies and practices

Researchers:
Mr. Kamal P Pokhrel (Sharma)
School of Education
Flinders University
Ph: +61 8 8201 3471

Supervisor(s):
Senior Lecturer Dr. Leigh Burrows
A/Prof. Dr. Kerry Bissaker
School of Education
Flinders University
GPO Box 2100, Adelaide SA 5001
Ph: +61 8 8201 3022

Description of the study:
This research is part of the project entitled “An exploration of experiences and perceptions of parents of children with a disability and education professionals regarding parental engagement with schools in a western district of Nepal: Implications for future policies and practices”. This project will explore the experiences and insights of parents with the schooling of their children with a disability and those of professionals and identify the factors that affect the engagement of parents to inform policy and school practices in this area in Nepal.

Purpose of the study:
This research project aims to explore experiences, perceptions and aspirations of parents and education professionals regarding parental engagement in the schooling of their children with disabilities. In addition, it will identify and analyse enabling and restrictive factors associated with parents’ engagement with the schools, with the aim of using the findings to contribute to improving policy and practices in the provision of special needs education in Nepal.

What will I be asked to do?
You are invited to participate in interviews with the researcher, Kamal Pokhrel, who will guide the inquiry to focus on your experiences and perceptions about schooling experiences of your children with a disability.
Interviews will take about 60 to 90 minutes. They will be tape recorded to assist in analysing the results. Once recorded, the discussions will be transcribed and translated, and all data stored on a password-protected computer. The transcribed data will be translated and then, on the completion of the research, the recordings will be retained for verification and secondary data analysis purposes. Your participation in this study is voluntary and you are free to decline to participate or withdraw from this study at any time for any reason.

What benefit will I gain from being involved in this study?
You will have an opportunity to express your experiences of being engaged in your child with a disability’s schooling. Your insights will be of great benefit in helping to reform school practices and policy in future.

Will I be identifiable by being involved in this study?
I will use your pseudonym and you will remain confidential in the research process and report. Your perspectives will not be linked directly to you. However, you will not be anonymous as other participants may know you. Once the inquiry has been transcribed and saved as a file, any identifying information will be removed, and the transcription file will be stored on a password-protected computer that only the researcher (Mr Kamal Pokhrel) will have access to.

Are there any risks or discomforts if I am involved?
It is unlikely that there would any risks or discomforts in being involved in this study. However, some of you may feel sadness or upset in telling sad experiences about your child with disability, as the area of discussion may raise sensitive issues. If you would like to bring a family member or a support person along for support, you are most welcome to do so. In any case, if you feel discomfort and wish to contact a counsellor, you may contact the following address for advice.

Nearest counselling services available:
Psycho-social Helpline Service, Butwal, Rupandehi *+ 977 9 802 637 11* *(Dr Arun Kunwar, Dr Manoj Dhungana and Dr Bikram Kafle)*

In addition, other possible burdens are the time required and travel costs associated with the participation in this research. You will be reimbursed for any two-way travel cost from your home to conversation venue and with a refreshment pack and a cup of tea for your time contribution to this study.

How do I agree to participate?
An introduction letter, this information sheet and a consent form are provided with this information pack. Please read them carefully. You will need to sign the attached consent form and give it to the researcher before the interview starts. You are able to ask for more information if you have any further questions. If you agree to participate please contact me on the following phone number.

+977 9849362062 (Kamal)

How will I receive feedback?
The conversation will be transcribed first from the audiotapes. If you wish to check the transcript you will be able to edit, add, or delete a portion of transcript if you wish to do so. The audiotapes will be stored securely for the purpose of verification or for secondary data analysis. Then, based on initial analysis; initial findings and conclusion of the study will be drawn. If you also wish to receive initial findings and conclusion of the research, please indicate in the box provided in the consent form. I will provide you the relevant materials as per your wish.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7476). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

*Similar but slightly adapted Information Sheets were provided to the parents of children with disabilities NOT enrolled in school and for the participants in the focus groups.

Appendix C (Nepali translation)

परिशिष्ट ग : जानकारी पत्र

श्री कमल प्रसाद पोखेल (शर्मा)
शिक्षा, मानविकी तथा कानुन विभाग
फ्लिन्डर्स विश्वविद्यालय, बेडफोर्ड पार्क, साउथ अष्ट्रेलिया, ५०४२
जिपिओ बक्स २१००, एडिलेड, ५००१
टेलिफोन: +६१ ८ ८२०१ ३४७१
इमेल: pokh0014 @flinders.edu.au
CRICOS Provider No 00114A

जानकारी पत्र

हाल विद्यालयमा अध्ययनरत अपाङ्गता भएका बालबालिकाका अभिभावकहरूका लागि

अनुसन्धानका शीर्षक : नेपालको एउटा पश्चिमी जिल्लामा अपाङ्गता भएका बालबालिकाका अभिभावकहरूको सहभागिता सम्बन्धमा स्वयम अभिभावकहरू र स्थानीय सरोकारवालाहरूको अनुभव र बुझाइको खोज : भविष्यका नीति तथा अभ्यासका लागि सुझाव

अनुसन्धानकर्ता :
कमल प्रसाद. पोखेल (शर्मा)
शिक्षा, मानविकी तथा कानुन संकाय
फि्लन्डर्स विश्वविद्यालय
फोन: +६१ ८ ८२०१ ४७१

सुपरिवेक्षकहरु :
बरिष्ठ प्राध्यापक डा. लिइ बरोज
सह–प्राध्यापक डा. केरी विसाकर
शिक्षा, मानविकी तथा कानुन विभाग
फ्लिन्डर्स विश्वविद्यालय, बेडफोर्ड पार्क साउथ अष्ट्रेलिया, ५०४२
जिपिओ बक्स २१००, एडिलेड, ५००१, फोन: +६१ ८८२०१ ३०२२

अध्ययनको विवरण

प्रस्तुत “नेपालको एउटा पश्चिमी जिल्लामा अपाङ्ता भएका बालबालिकाको अभिभावकहरूको सहभागिता सम्बन्धमा अभिभावकहरू स्वयम र स्थानीय सरोकारवालाहरूको अनुभव र बुझाइको खोज : भविष्यका नीति तथा अभ्यासका लागि सुझाव” विषयक अनुसन्धानले विशेष आवश्यकता भएका विद्यार्थीका अभिभावकहरुको शिक्षामा संलग्नता सम्बन्धमा ती अभिभावक स्वयम तथा स्थानीय सरोकारवालाहरूको अनुभव र बुझाइको विश्लेषण गरी नेपालको भावी नीति तथा विद्यालयका अभ्यासहरुको सुधारका लागि सुझाव दिने अपेक्षा गरिएको छ ।

अनुसन्धानको उद्देश्य:

यस अनुसन्धानको उद्देश्य विशेष आवश्यकता भएका विद्यार्थीका अभिभावकहरुको शिक्षामा संलग्नता सम्बन्धमा ती अभिभावक स्वयम तथा स्थानीय सरोकारवालाहरूको के कस्तो अनुभव तथा बुझाइ रहेको छ पत्ता लगाउनु, अभिभावकहरुको संलग्नतामा सहयोग र अवरोध पुराउने तत्वको पहिचान गर्नु र विशेष आवश्यकता भएका विद्यार्थीको शिक्षामा सुधार ल्याउन भविष्यका नीति तथा विद्यालयका अभ्यासहरुको परिमार्जनका लागि सुझाव दिनु रहेको छ । उक्त कार्यका लागि यहाँको अनुभव समेटनु पर्ने हुँदा व्यक्तिगत कुराकानी वा अन्तरवार्तामा यहाँको सहभागिताका लागि आमन्त्रण गरिएको छ ।

यस अनुसन्धान मेरो भूमिका के हुन्छ ?

उल्लिखित कार्यक्रममा सहभागिताका लागि यहाँलाई आमन्त्रण गरिएको छ । विशेष आवश्यकता भएका विद्यार्थीका अभिभावकहरुको शिक्षामा संलग्नता सम्बन्धमा तपाईंको अनुभव तथा बुझाइ तथा अभिभावकहरुको संलग्नतामा सहयोग र अवरोध पुराउने तत्वको पहिचान

सम्बन्धी अनसुन्धानकर्ता कमल पोखेलले सोध्नुहुने प्रश्नका सम्बन्धमा आफ्ना धारणा राखि दिनु हुनेछ भन्ने आसा गरिएको छ । यो छलफल एक देखि डेढ घण्टासम्मको हुनेछ । तपाईंका विचारहरु बिश्लेषण गर्नका लागि छलफललाई टेप रेकर्डिङ, लिप्यान्तरण तथा अनुवाद गरिनेछ । उल्लिखत कार्यमा गोपनियता कायम गर्न अनसुन्धानकर्ताले प्रयोग गर्ने कम्प्युटरमा पासवर्डको प्रयोग गरिने छ । अनुसन्धानका क्रममा यहाँले व्यक्त गर्नुभएका विचारहरु हरतरहले गोप्य रहने छन् । यस सन्दर्भमा शोधपत्र लगायतका लेख रचना प्रकाशन गर्दा यहाँको नाम उल्लेख गरिने छैन । नाम परिवर्तन गरी यहाँका विचारहरु प्रकाशन गर्न भने यसले वाधा पुऱ्याउने छैन । छलफलका क्रममा कुनै खास प्रश्नको उत्तर नदिन तथा छलफल कार्यक्रमको जुनसुकै समयमा असहभागिता जनाउन यहाँलाइ पुरै स्वतन्त्रता हुने छ ।

यस अनुसन्धानबाट मलाइ के लाभ हुन्छ ?

तपाईंको अनुभव, भोगाइ तथा विचारका आधारमा विशेष आवश्यकता भएका विद्यार्थीका अभिभावकहरुको शिक्षामा संलग्नता सम्बन्धमा अनुभव तथा बुझाइ के कस्तो छ जानकारी हुने तथा अभिभावकहरुको संलग्नतामा सहयोग र अवरोध पुराउने तत्वको पहिचान हुने र ती विद्यार्थीको शिक्षामा सुधार ल्याउन भविष्यका नीति तथा विद्यालयका अभ्यासहरुको परिमार्जनका लागि मद्दत पुग्नेछ । यहाँका विचार तथा अनुभवले भविष्यमा यहाँहरु जस्ता अभिभावकको शिक्षामा संलग्नता अभिवृद्धि भई नेपालका विशेष आवश्यकता भएका बालबालिकाको शिक्षामा पँहुच तथा सहभागिता तथा गुणस्तर वृद्धि हुने र उनीहरुको सिकाइ तथा विकासमा महत्वपूर्ण योगदान पुग्नेछ । यसका अतिरिक्त छलफलमा सहभागी भई आफ्नो अमूल्य समय तथा विचार व्यक्त गरिदिनु भएकोमा यँहालाई चिया, खाजा र यातायात खर्च उपलब्ध गराइने छ ।

यस अनुसन्धानमा सहभागी हुदा मेरो व्यक्तिगत पहिचान हुन्छ कि ?

अनुसन्धानका क्रममा यहाँले व्यक्त गर्नुभएका विचारहरु हरतरहले गोप्य रहने छन् । यस सन्दर्भमा शोधपत्र लगायतका लेख रचना प्रकाशन गर्दा यहाँको नाम उल्लेख गरिने छैन । नाम परिवर्तन गरी यहाँका विचारहरु प्रकाशन गर्न भने यसले वाधा पुऱ्याउने छैन । तर तपाई अज्ञात भने रहनु हुने छैन । छलफलका क्रममा कुनै खास प्रश्नको उत्तर नदिन तथा छलफल कार्यक्रमको जुनसुकै समयमा असहभागिता जनाउन यहाँलाइ पुरै स्वत्रन्तता हुने छ । छलफलमा प्राप्त सूचना तथा तथ्याङ्क विश्लेषणका कार्यलाई सहज तुल्याउन छलफल टेप रेकर्डिङ् गर्नु पर्ने हुँदा यहाँको मन्जुरीनामा आवश्यक हुन्छ । यसका लागि यहाँको नाम गोप्य रहने शर्त उल्लेख गरिएको मन्जुरीनामा पत्रमा हस्ताक्षर गरी आफ्ना विचार तथा धारणा रेकर्ड गर्ने स्वीकृति दिन पर्ने हुन्छ । संकलित सूचना तथा तथ्याङ्क विश्लेषणकै क्रममा लिप्यान्तरण तथा अनुवाद गर्दा कुनै विशेषज्ञ सेवाको आवश्यकता पर्ने भएमा उक्त विशेषज्ञलाई सूचनाको गोपनियता कायम गर्ने शर्त उल्लेख गरिएको दस्तवेजमा हस्ताक्षर गराई यहाँको पहिचान गोप्य राखिने छ ।

यस अनुसन्धानमा सहभागी हुदा मलाइ कुनै नकारात्मक असर पर्छ कि ?

यस अनुसन्धानमा सहभागी हुँदा जोखिमको अपेक्षा गरिदैन र कुनै पनि नकारात्मक असर पनि नपर्ने अपेक्षा गरिएको छ । यसमा सहभागी भई आफ्ना अनुभव तथा विचारहरु अभिव्यक्त गरे वापत यहाँको निजी वा पेशागत जीवनमा कुनै प्रकारको असर पर्ने छैन । यद्यपि यहाँले आफ्नो जीवनमा घटेका महत्वपूर्ण तथा दुखद अनुभव सुनाउदा केही भावुकता तथा क्षणिक नैरास्यता नआउला भन्न सकिदैन । तपाइले चाहेमा आफूसंग कुनै आफन्त वा सहयोगी पनि ल्याउन सक्नु हुने छ । कसै गरी तपाइले धेरै नै निराशा अनुभव गर्नु भयो तपाईले परामर्शका लागि तलको ठेगानामा सम्पर्क गर्न पनि सक्नु हुनेछ ।

सबैभन्दा नजिक उपलब्ध परामर्श सेवाहरु
मनोसामाजिक सहायता सेवा, वुटवल, रुपन्देही + ९७७ ९ ८०२ ६३७ ११ (डा. अरुण कुँवर, डा. मनोज ढुंगाना, र डा. विक्रम काफ्ले)

यसका अतिरिक्त अन्य सम्भावित बोझमा यसका लागि चाहिने समय तथा यस अनुसन्धानमा सहभागी हुँदाको आवतजावत यातायात खर्च हुनेछ । यस अनुसन्धानमा योगदान गरे घरदेखि कुराकानी हुने स्थानसम्मको वापत तपाइलाई लागेको आवतजावत यातायात खर्च र चियानास्ताको प्रबन्ध गरिएको छ ।

यस अनुसन्धानमा सहभागिताका लागि मैले कसरी स्वीकृति दिनु पर्ला ?

यस अनुसन्धानमा सहभागी हुनु भन्दा पहिले यहाँलाई मेरो परिचय उल्लेख भएको पत्र, यो जानकारी पत्र र मञ्जुरी सम्बन्धी पत्र उपलब्ध गराइने छ । अतः आफ्नो नाम गोप्य रहने शर्तमा छलफलमा सहभागी हनु मन्जुर छु भनी उल्लेख गरिएको मन्जुरीनामा पत्रमा हस्ताक्षर गरी आफ्ना विचार तथा धारणा टेपरेकर्ड गर्ने स्वीकृति दिन सक्नुहुनेछ । उक्त जानकारी पत्र अध्ययन गरेपश्चात अनुसन्धानमा सहभागी हुने वा नहुने भन्नेमा निर्णय गर्न यहाँलाई पर्याप्त समय दिइने छ । कुनै विषयमा थप जानकारी चाहिएमा मलाइ सम्पर्क गर्न सक्नु हुनेछ र यस अनुसन्धानमा सहभागी हुन स्वीकार गर्नु भएमा कृपया मलाइ यस मोबाइल नम्बरमा सम्पर्क गर्नु होला ।

+ ९७७ ९८४९३६२०६२ (कमल)

यस अनुसन्धानमा सहभागिताको पृष्टपोषण मैले कसरी प्राप्त गर्ने ?

सर्वप्रथम टेप रेकर्डिङ् गरिएको छलफललाई लिप्यान्तरण गरिने छ। यदि यहाँले हेर्न चाहेको खण्डमा छलफलको उक्त लिप्यान्तरण यहाँलाई उपलब्ध गराइने छ जसमा यहाँले कुनै खण्ड संशोधन, थप्ने वा हटाउन सक्नु हुनेछ। टेप रेकर्डिङ् गरिएको छलफललाई प्रमाणीकरण र पछि पुन द्वितीय चरणको विश्लेषणका लागि गोप्य रुपमा सुरक्षित साथ राखिने छ। अनि प्रारम्भिक विश्लेषण पश्चात अध्ययनका प्रारम्भिक प्राप्ति र निष्कर्ष निकालिने छ। यदि तपाई अनुसन्धानको प्रारम्भिक प्राप्ति र निष्कर्ष पनि हेर्न इच्छुक हुनुहुन्छ भने मञ्जुरीनामामा दिइएको स्थानमा उल्लेख गर्न सक्नु हुनेछ। यहाको रुचि बमोजिमका सामग्री अध्ययनको समाप्ति पश्चात यहाँलाई पठाइने छ।

यस जानकारी पत्र अध्ययन गर्ने समय दिनु भएकोमा हार्दिक धन्यवाद छ। साथै यस जानकारी पत्रको अध्ययन पश्चात यस अनुसन्धानमा सहभागी हुनु हुनेछ भन्ने आशा लिएका छौं।

यो अनुसन्धान फ्लिन्डर्स विश्वविद्यालय सामाजिक तथा व्यवहारिक अनुसन्धान नैतिक समिति द्वारा स्वीकृत गरिएको छ (परियोजना नं. ७४७६)। यस सम्बन्धी थप जानकारीका लागि समितिको कार्यकारी अधिकृतलाई देहायको ठेगानामा सम्पर्क राख्न सक्नु हुनेछ। फोनः +६१ ८८२०१३११६, फयाक्सः +६१ ८८२०१२०३५ अथवा इमेल : human.researchethics@flinders.edu.au

inspiring
achievement

Appendix D: Consent forms

Flinders
UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH*

For parents of children with disabilities currently enrolled in schools

An exploration of experiences and perceptions of parents of children with a disability and education professionals regarding parental engagement with schools in a western district of Nepal: Implications for future policies and practices

I ………………………………………………………………………………………, parent of child with a disability currently enrolled in the school, being over the age of 18 years hereby consent to participate as requested in the interview for the research titled "An exploration of experiences and perceptions of parents of children with a disability and education professionals regarding parental engagement with schools in a western district of Nepal: Implications for future policies and practices".

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:

- I am free to withdraw from the project at any time and I am free to avoid answering any particular question without disadvantage.
- While the information gained in this study will be published as explained, I will not be identified in the report, and individual information will remain confidential. However, I understand that I will not be anonymous.

6. I wish to receive (please tick the relevant box)
   (1) Transcript of the interview . ☐
   (2) Initial findings ☐
   (3) Conclusion of the study ☐

Participant's signature: ……………………………… **Date:** …………………..

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's signature: ……………………………… **Date:** ……………………

Researcher's name: Kamal Pokhrel Sharma

NB:Two signed copies should be obtained.

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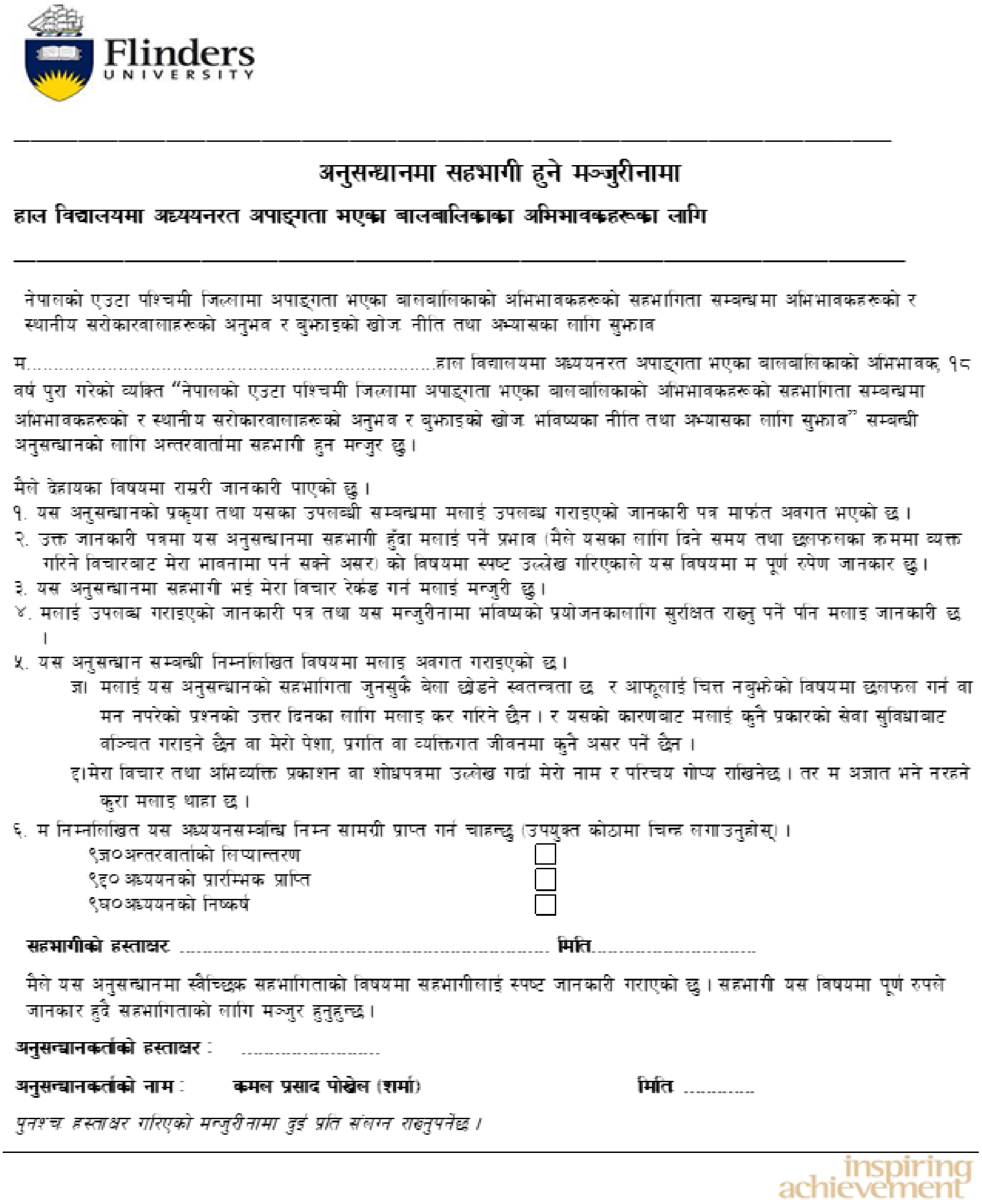
*Similar type of Consent Forms with appropriate adaptations were provided separately to parents of children with disabilities currently NOT enrolled in schools, resource teachers, mainstream teachers, head teachers, members of School Management Committee, members of Parent Teacher Association, professionals who were working with the government at the local level.

Appendix D (Nepali translation)

परिशिष्ट घ : अनुसन्धानमा सहभागी हुने मञ्जुरीनामा



अनुसन्धानमा सहभागी हुने मञ्जुरीनामा

हाल विद्यालयमा अध्ययनरत अपाङ्गता भएका बालबालिकाका अभिभावकहरूका लागि

नेपालको एउटा पश्चिमी जिल्लामा अपाङ्गता भएका बालबालिकाको अभिभावकहरूको सहभागिता सम्बन्धमा अभिभावकहरूको र स्थानीय सरोकारवालाहरूको अनुभव र बुझाइको खोज नीति तथा अभ्यासका लागि सुझाव

म...हाल विद्यालयमा अध्ययनरत अपाङ्गता भएका बालबालिकाको अभिभावक, १८ वर्ष पुरा गरेको व्यक्ति "नेपालको एउटा पश्चिमी जिल्लामा अपाङ्गता भएका बालबालिकाको अभिभावकहरूको सहभागिता सम्बन्धमा अभिभावकहरूको र स्थानीय सरोकारवालाहरूको अनुभव र बुझाइको खोज भविष्यका नीति तथा अभ्यासका लागि सुझाव" सम्बन्धी अनुसन्धानको लागि अन्तरवार्तामा सहभागी हुन मन्जुर छु।

मैले देहायका विषयमा राम्ररी जानकारी पाएको छु।

१. यस अनुसन्धानको प्रकृया तथा यसका उपलब्धी सम्बन्धमा मलाई उपलब्ध गराइएको जानकारी पत्र मार्फत अवगत भएको छु।

२. उक्त जानकारी पत्रमा यस अनुसन्धानमा सहभागी हुँदा मलाई पर्ने प्रभाव (मैले यसका लागि दिने समय तथा छलफलका क्रममा व्यक्त गरिने विचारबाट मेरा भावनामा पर्न सक्ने असर) को विषयमा स्पष्ट उल्लेख गरिएकाले यस विषयमा म पूर्ण रुपेण जानकार छु।

३. यस अनुसन्धानमा सहभागी भई मेरा विचार रेकर्ड गर्न मलाई मन्जुरी छ।

४. मलाई उपलब्ध गराइएको जानकारी पत्र तथा यस मन्जुरीनामा भविष्यको प्रयोजनकालागि सुरक्षित राख्नु पर्ने पनि मलाइ जानकारी छ।

५. यस अनुसन्धान सम्बन्धी निम्नलिखित विषयमा मलाइ अवगत गराइएको छ।

   ज। मलाई यस अनुसन्धानको सहभागिता जुनसुकै बेला छोड्ने स्वतन्त्रता छ र आफूलाई चित्त नबुझेको विषयमा छलफल गर्न वा मन नपरेको प्रश्नको उत्तर दिनका लागि मलाइ कर गरिने छैन। र यसको कारणबाट मलाई कुनै प्रकारको सेवा सुविधाबाट वञ्चित गराइने छैन वा मेरो पेशा, प्रगति वा व्यक्तिगत जीवनमा कुनै असर पर्ने छैन।

   द।मेरा विचार तथा अभिव्यक्ति प्रकाशन वा शोधपत्रमा उल्लेख गर्दा मेरो नाम र परिचय गोप्य राखिनेछ। तर म अज्ञात भने नरहने कुरा मलाइ थाहा छ।

६. म निम्नलिखित यस अध्ययनसम्बन्धि निम्न सामग्री प्राप्त गर्न चाहन्छु (उपयुक्त कोठामा चिन्ह लगाउनुहोस्)।

   ९ज०अन्तरवार्ताको लिप्यान्तरण ☐
   ९द० अध्ययनको प्रारम्भिक प्राप्ति ☐
   ९घ०अध्ययनको निष्कर्ष ☐

सहभागीको हस्ताक्षर .... **मिति**..................................

मैले यस अनुसन्धानमा स्वैच्छिक सहभागिताको विषयमा सहभागीलाई स्पष्ट जानकारी गराएको छु। सहभागी यस विषयमा पूर्ण रुपले जानकार हुँदै सहभागिताको लागि मञ्जुर हुनुहुन्छ।

अनुसन्धानकर्ताको हस्ताक्षर : ....

अनुसन्धानकर्ताको नाम : **कमल प्रसाद पोखेल (शर्मा)** **मिति** ....

पुनश्च हस्ताक्षर गरिएको मन्जुरीनामा दुई प्रति संलग्न राख्नुपर्नेछ।

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Appendix E: Guidelines for informal interview conversation

<u>Participants of the individual conversations</u>

A) Parents whose children are enrolled in the two integrated schools operated for children who have two different types of disability (will include local to far distant parents)
B) Parents whose children with a disability are not enrolled in the school

<u>Part 1: Demographic information</u>

Name of parent (pseudonym): …….. Sex: ……….. Age range (e.g. 30-40 etc.): …….

Caste/ethnicity: ……………………. Religion: … Education: …. Occupation: ...

Name of child (pseudonym): ……… Sex: …….. Age range (5-10, 10-15 etc.): ………

School (pseudonym): ……………….. Disability category: …….. Grade: ……

I will start with a question – *'Could you please tell me about yourself?' (with some prompts)* in order to collect the general or demographic information (no identifying details will be recorded).

<u>Part 2: Experience with their child with a disability and their schooling</u>

I will ask these core questions related to their experiences/stories about their children with a disability and their schooling.

1. Please tell me about your experience of parenting a child with a disability.
2. When did you consider schooling options? Or Have you ever thought of school for your child?
3. Who/what influenced your thinking?
4. Please tell me about your experience when you first visited your child's school.
5. Tell me about your experience about your involvement in the school.
6. What are your wishes/dream for your child?
7. What are your expectations from school/education?

I will also use prompts such as 'that is really interesting, could you tell more about it'; 'could you give me an example of that'; 'how would that look like'; 'why do you think so'; 'what happened then'; 'when did that happen' and so on. While posing the questions/prompts, I will also be sufficiently careful not to interrupt their flow of speech. Some of these questions will be modified when communicating with the parents of non-enrolled children. In addition, if required I will adapt the vignettes prepared as samples during the proposal preparation stage, incorporating the real stories of parents obtained in the informal interview conversations with parents.

Appendix E (Nepali translation)

परिशिष्ट ङ : अभिभावकहरुसंगको अनौपचारिक अन्तरवार्ता कुराकानीका लागि निर्देशिका

व्यक्तिगत कुराकानी वा अन्तरवार्ताका सहभागीहरु

क) समाहित शिक्षा सञ्चालन भएको विद्यालयमा अध्ययनरत अपाङ्ता भएका बालबालिकाका अभिभावकहरु

ख) विद्यालयमा भर्ना नभएका / नगरिएका अपाङ्ता भएका बालबालिकाका अभिभावकहरु

खण्ड - क : सामान्य डेमोग्राफिक जानकारी

अभिभावकको नाम (छद्म/ काल्पनिक नाम): .... लिङ्गः .... उमेर समूह (३० देखि ४० आदि): ......
जात/ जातिः .... धर्मः .... शिक्षा : .... पेशा : ....
बच्चाको नाम (छद्म/ काल्पनिक नाम): .... लिङ्गः .... उमेर समूह (५ देखि १० आदि): ......
कक्षा : ...... विद्यालयको नाम (छद्म/ काल्पनिक नाम): .... अपाङ्ताको प्रकार : ....

यी सामान्य डेमोग्राफिक सूचना संकलन गर्नका लागि सर्वप्रथम म ‘कृपया तपाईंको बारेमा केही कुरा बताइ दिनुहोस्’ वा यस्तै प्रकारका तत्काल आवश्यक ठानिएका प्रश्नहरु सोध्ने छु ।

खण्ड - ख : अपाङ्ता भएका बालबालिकाका अभिभावकको ती बालबालिकासंगको तथा उनीहरुको शिक्षा सम्बन्धी अनुभवहरु

अपाङ्ता भएका बालबालिकाका अभिभावकसंग उनीहरुको ती बालबालिकासंगको तथा तिनको शिक्षा बारेको अनुभवहरु सम्बन्धी निम्नलिखित मुख्य प्रश्नहरु सोध्ने छु ।

1. कृपया अपाङ्ता भएको बालबालिकाका अभिभावक हुँदा वा अभिभावकत्व गर्दाको अनुभव बारेमा केही कुरा बताइ दिनुहोस् ।
2. तपाईंको बच्चाका लागि तपाईंले विद्यालय शिक्षाबारेमा कहिले देखि सोच्नु भयो ? वा तपाईं कहिल्यै मेरो बच्चा विद्यालय पनि जाने छ भन्ने ठान्नु भएको थियो ?
3. तपाईं यसबारेको सोंचका लागि कोबाट वा के कारणबाट प्रभावित हुनु भयो ?
4. तपाईंको बच्चाका विद्यालयमा पहिलो पल्ट जाँदाको अनुभव बारेमा कृपया केही कुरा बताइ दिनुहोस् ।
5. विद्यालयमा तपाईं सहभागिता जनाएको वा आफै सरिक भई काम गरेको तपाईको अनुभव बतानुहोस् ।
6. तपाईंको बच्चाको भविष्यका बारेमा तपाईंको चाहना । सपना के छन् ?
7. यसका लागि विद्यालयबाट तपाईका अपेक्षाहरु के के छन् ?

यी प्रश्नहरुका अतिरिक्त म तत्काल आवश्यक ठानिएका अन्य प्रश्नहरु जस्तै “यो कुरा सांच्चै कै रोचक छ, यस बारे थप बताइ दिनुहोस न”, “कृपया यसको एउटा उदाहरण भन्नुहोस् न”, “त्यो कस्तो देखिन्थ्यो होला ?”, “तपाईं के कारणले गर्दा त्यस्तो ठान्नुहुन्छ ?”, “त्यस पछि के भयो ?”, “त्यो कहिले भयो ?” आदि सोध्ने छु । माथि उल्लेखित मूल प्रश्न वा अन्य प्रश्नहरु राख्दा सहभागीहरुको संवाद प्रवाहमा कुनै पनि हिसाबले अवरोध नहुने कुरामा प्रशस्त सावधानी अपनाइने छ । विद्यालयमा भर्ना नभएका / नगरिएका अपाङ्ता भएका बालबालिकाका अभिभावकहरुसंग कुराकानी गर्दा माथि उल्लेखित केही प्रश्नमा आवश्यकता अनुसार परिमार्जन गरिने छ । यसका अतिरिक्त आवश्यकता अनुसार अभिभावकहरुसंगको कुराकानी वा अन्तरवार्तामा लक्षित समूह छलफलका लागि प्रस्तावनाका लागि नमूनाका रुपमा तयार गरिएका दृष्टान्त (vignettes) लाई समेत प्रयोग गरिने छ ।

Appendix F: Guidelines for focus group discussions (FGD)

Participants of the focus group discussions

A) Local educators: mainstream teachers and resource teachers (a resource teacher is a teacher assigned to teach special needs children) from the schools (FGD 1)
B) Local educators: head teachers and/or assistant head teachers of the schools (FGD 2)
C) Community members: community representative in school committees (members of school management committee or parent–teacher association) from the schools (FGD 3)
D) Local government officials: school supervisors and resource persons – staff at district education office responsible for school supervision and teacher support for their cluster, i.e. associated with the two schools plus heads of assessment centres and village palikas or municipalities associated with data of non-enrolling children (FGD 4)

Vignettes[31] and questions for focus group discussion

Vignette One

Asmita is 17 years old now. She cannot speak and is not able to learn as per the level of her peers. She likes to listen to music. Her family migrated to this place three years ago. Her parents were sending Asmita to a school near their old place. But when they migrated here, it took one year for them to learn that there is a school in their locality which can cater for the needs of children like their daughter Asmita. Asmita started attending the school two years ago. Laxmi, her mother, when asked to tell her experiences about her engagement in school activities, said, ‘I would go to the school in the morning to leave her and in the afternoon to bring her home. Sometimes I would also let her follow her peers to the school.’ She added, ‘I would meet the caretaker sometimes; and once, Asmita’s teacher also asked me to visit him.’ However, in Asmita’s previous school (abroad), parents would be invited to visit the school regularly. All parents were taught how to help the children brush their teeth, take a shower and trim their nails. Therefore, Asmita is able to do these things by herself. She added that, ‘if the current school had invited me, I would have been able to explain to the other parents how we parents can help our children do these things at home’.

Vignette Two

When Buddhi was born, a doctor told his mother that he would not live his life like a ‘normal child’ because of developmental delays. He is 12 years old now. He cannot speak. He could walk with the support of a wall or a rope. His parents tried to enrol him in school, but no public or private school would admit him. Later, his father died. His mother says, ‘If he were in school from 10 to 3, it would really help the family.’ Instead, ‘Buddhi has to spend his entire day locked in a room at home.’ His mother said, ‘I would offer him food and tea. I have also put a toilet pot in the room if he needs. I have a small job. I must take care of his elder brother too and I have to do all household chores.’ She also then added that, ‘This must be due to some sort of our past sins so that the Deity gave us this curse. We have no ways but to accept it, live with it, it’s our fate.’

Vignette Three

Balkumari is a 7-year-old girl diagnosed with an intellectual disability. Regarding schooling, her father and

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[31] Vignettes are drawn on the real stories of parents participated in this research and some instances are alo adapted from Barriga’s (2011) research from far western part of Nepal.

mother had differing opinions. Her father would say that she could not go to the same mainstream school, with her brother and sister, because of her intellectual difficulty. Instead, he wanted Balkumari to enrol in a class for children with intellectual disabilities with a residential facility, though it is quite far from their home. But her mother did not want to enrol her in such a distant school. She thought that she would not be able to manage and it would be painful for both Balkumari and her parents. She thought that sending Balkumari to the residential school would separate her from parents and family. However, her father did not listen to her mother and decided to enrol Balkumari in a residential integrated school. Her father usually visits the school to collect her before the vacation and leaves her when school classes begin. On some occasions, maybe once in a year, he would also be invited by the resource teacher to discuss Balkumari's learning and progress.

Questions for focus group discussion.

What is your response to the stories presented here?
According to your view, what would parents think of this situation?
How would you support a family like this?
What do you do in this school to ensure high quality parental engagement?
What possibilities are there to engage such parents in your school?

Appendix F (Nepali translation)

परिशिष्ट च : प्रधानाध्यापक/शिक्षक समुदाय प्रतिनिधि/सरकारी अधिकारीसंगको लक्षित समूह छलफलका लागि

लक्षित समूह छलफलका सहभागीहरु

क) स्थानीय शिक्षक । शिक्षा कर्मी : छनोट गरिएका विद्यालयका साधारण विद्यार्थीलाई पढाउने शिक्षक र स्रोत शिक्षक (अपाङ्ता भएका विद्यार्थीलाई पढाउने तोकिएका शिक्षक) (लक्षित समूह छलफल १)

ख) छनोट गरिएका विद्यालयका प्रधानाध्यापक वा सहायक प्रधानाध्यापकहरु (लक्षित समूह छलफल २)

ग) समुदायका सदस्य : छनोट गरिएका विद्यालयको समितिहरुमा प्रतिनिधित्व गर्ने समुदायका प्रतिनिधि (विद्यालय व्यवस्थापक समितिको अध्यक्ष वा सदस्य र अभिभावक शिक्षक संघका अध्यक्ष वा सदस्य) (लक्षित समूह छलफल ३)

घ) सरकारको स्थानीय स्तरमा कार्यरत कर्मचारी : विद्यालय निरिक्षकहरु, स्रोत व्यक्ति -जिल्ला शिक्षा कार्यालयका तोकिएको क्षेत्रका विद्यालय सुपरिवेक्षण र शिक्षक सहायताको जिम्मेवारी पाएका कर्मचारी, ती दुई विद्यालयसंग सम्बन्धित दुई जना) र विद्यालयमा भर्ना नभएका । नगरिएका अपाङ्ता भएका बालबालिकाको सूचना राख्ने आँकलन केन्द्र र गाउँ वा नगर पालिकाका प्रमुखहरु (लक्षित समूह छलफल ४)

सामान्य डेमोग्राफिक जानकारी

उपस्थित सहभागी संख्या : .... पुरुष : .... महिला : ......

विद्यालयको नाम (छद्म/ काल्पनिक नाम): .... विद्यालयको प्रकार (अपाङ्ताका आधारमा)

लक्षित समूह छलफलका लागि दृष्टान्त [32](vignette)र प्रश्नहरु

दृष्टान्त (vignette): एक

अस्मिता जो अहिले १८ वर्षकी भइन, लक्ष्मी र श्यामकी छोरी हुन् । उनी बोल्न र आफूसरहका साथीहरुकै स्तरमा सिकाइ गर्न सक्दैनन् । उनलाई गीत बजेको सुन्न मन पर्छ । लक्ष्मी र श्यामले आफू यस अधि बसोबास गरिरहेको ठाँउमा अस्मितालाई विद्यालय पठाएका थिए । तर यस ठाउमा आए पछि अस्मितालाई पनि पठाउन मिल्ने विद्यालय छ भन्ने थाहा पाउन उनलाई एक वर्ष लाग्यो । उनले दुई वर्ष अघिदेखि मात्र आफ्नो गाउँको विद्यालयमा जान शुरु गरिन । उनका कक्षाका सबै साथीहरु सात देखि नौ वर्ष बीचका छन् । विद्यालयका कियाकलाप वा गतिविधिहरुमा उनको संलग्नताको अनुभवका बारेमा लक्ष्मीसंग कुरा गर्दा उनी भन्छिन, "म अस्मितालाई पुराउन स्कूलसम्म जान्छु, अनि साँझ लिन पनि जान्छु । कहिलेकाहि साथीहरुसंथयग लगाइ पठाइदिन्छु" । उनी थप्छिन, "कहिलेकाहि आयालाई भेटछु, अस्मिताको शिक्षकले पनि एक पटक बोलाउनु भएको थियो" । "यस अघिको विद्यालयमा भने अभिभावक र शिक्षक बिच निरन्तर भेटघाट हुन्थ्यो । सबै अभिभावकलाई घरमा बच्चालाई दात माझ्न, नुहाउन, नङ्ग काटने तरिकाहरु सिकाइएको थियो । त्यो भएर अस्मितालाई पनि यी कुरा गर्न आउछ" । "मलाइ पनि अहिलेको विद्यालयले बोलाएमा यस्ता बच्चालाई घरमा सिकाउन सकिने कुराका बारे म पनि अरु अभिभावकलाई बताउन सक्थे" ।

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[32] यहाँ प्रयोग गरिएका सबै दृष्टान्तहरु अभिभावकहरुसँगको अनौपचारिक कुराकानी अन्तरवार्तामा प्राप्त घटना विवरणमा आधारित गरिएका छन र साथै केही प्रसंग बरिगाको सुदुर पश्चिम नेपालमा गरिएको अनुसन्धान सम्बन्धी अग्रेजीमा लेखिएको पुस्तक (Barriga (2011) बाट समेतबाट आवश्यक परिमार्जन सहित साभार गरिएका हुन .

दृष्टान्त (vignette): दुई

जब कृष्ण जन्मिए एक जना डाक्टरले उनको आमालाई भने कि बुद्धिले उनको ढीलो शारीरिक विकासक्रमले गर्दा अरु सामान्य बच्चाले जस्तो जीवन जिउन सक्ने छैन । उनी अहिले १२ वर्षका भए, उनी बोल्न र हिडडुल गर्न सक्दैनन् । उनका बाबु आमाले उस्लाई विद्यालयमा भर्ना गर्न खोजेका थिए तर कुनै पनि सरकारी वा निजी विद्यालयले उस्लाई भर्ना गर्न मानेनन । पछि उनका बाबु पनि मरे । उनकी आमाले भन्छिन, "यदि उ १० बजे देखि ३ बजेसम्म विद्यालयमा हुँदो हो त हाम्रो परिवारलाई साच्चै कै सहायता पुग्ने थियो" । तर बुद्धिलाई पूरै दिन भरि घरको कोठाभित्र थुनिएर बस्नु पर्छ । उनकी आमाले भन्छिन, "म उस्लाई खाना चिया राखी दिन्छु । उसलाई कोठामा दिसा पिसाब गर्नलाई एउटा भाँडो पनि राखी दिएको छु । मैले एउटा सानो जागीर पनि गरिरहेकी छु । उसका दाइलाई पनि मैले हेरचाह गर्नुपर्छ र अन्य घरायसी कामधन्धा पनि सम्हाल्नु पर्छ ।" उनले थप भनिन, "यो पक्कै पनि हाम्रो पूर्व जन्मको पापले दैवले हामीलाई दिएको सजाय हुनुपर्छ । हामीसंग यसलाई स्वीकार्नु, यससंगै बाच्नु बाहेक अरु केही उपाय छैन, यो नै हाम्रो भाग्य हो"

दृष्टान्त (vignette): तीन

बालकुमारी बौद्धिक अपाङ्ता भएकी सात वर्षकी बालिका हुन । उनलाई विद्यालय पठाउने बारेमा उनका बाबु र आमाको भिन्न भिन्न विचार छन् । उनका बाबु भन्छन कि उनको बौद्धिक अपाङ्ताको कारणले गर्दा उनी उनका भाइ बहिनी पढ्न जाने साधारण विद्यालयमा जान सक्दैनिन । बरु उनी बालकुमारीलाई आवास सुविधा भएको बौद्धिक अपाङ्ता भएका बालबालिका पढने विद्यालयमा भर्ना गर्न चाहन्छन, यद्यपि यो विद्यालय उनीहरुको घरदेखि अलि टाढा नै छ । तर उनकी आमा भने त्यति टाढाको विद्यालयमा उनलाई भर्ना गर्न चाहदैनिन । उनी ठान्छिन कि उनको छोरीले त्यहाँ व्यवस्थापन गर्न सक्ने छैनिन, यो बालकुमारी र उनका बाबुआमा दुबैका लागि दुःखदायी हुने छ । उनी यो पनि ठान्छिन कि बालकुमारीलाई आवास सुविधा भएको विद्यालयमा पठाउने हो भने उनलाई बाबुआमा र परिवारबाट छुट्टिनु पर्ने हुन्छ । तर उनको बुबाले उनको आमाका यी कुरा सुनेनन र बालकुमारीलाई त्यही समाहित शिक्षा प्रदान गर्ने विद्यालयमा भर्ना गर्ने निधो गरे । उनका बुबाले विद्यालयमा लामो विदा शुरु हुँदा लिन जान्छन र विद्यालय सञ्चालन हुँदा उनलाई पुर्‍याउन जाने गर्दछन् । कुनै कुनै अवसरमा, वर्षको एक पटक जति, बालकुमारीको सिकाइ र प्रगतिबारेमा छलफल गर्न उनको बुबालाई स्रोत शिक्षकले आमन्त्रण पनि गर्ने गर्दछन ।

लक्षित समूह छलफलका लागि प्रश्नहरु

१. यी दृष्टान्तको बारेमा तपाईंको प्रतिक्रिया के छ ?

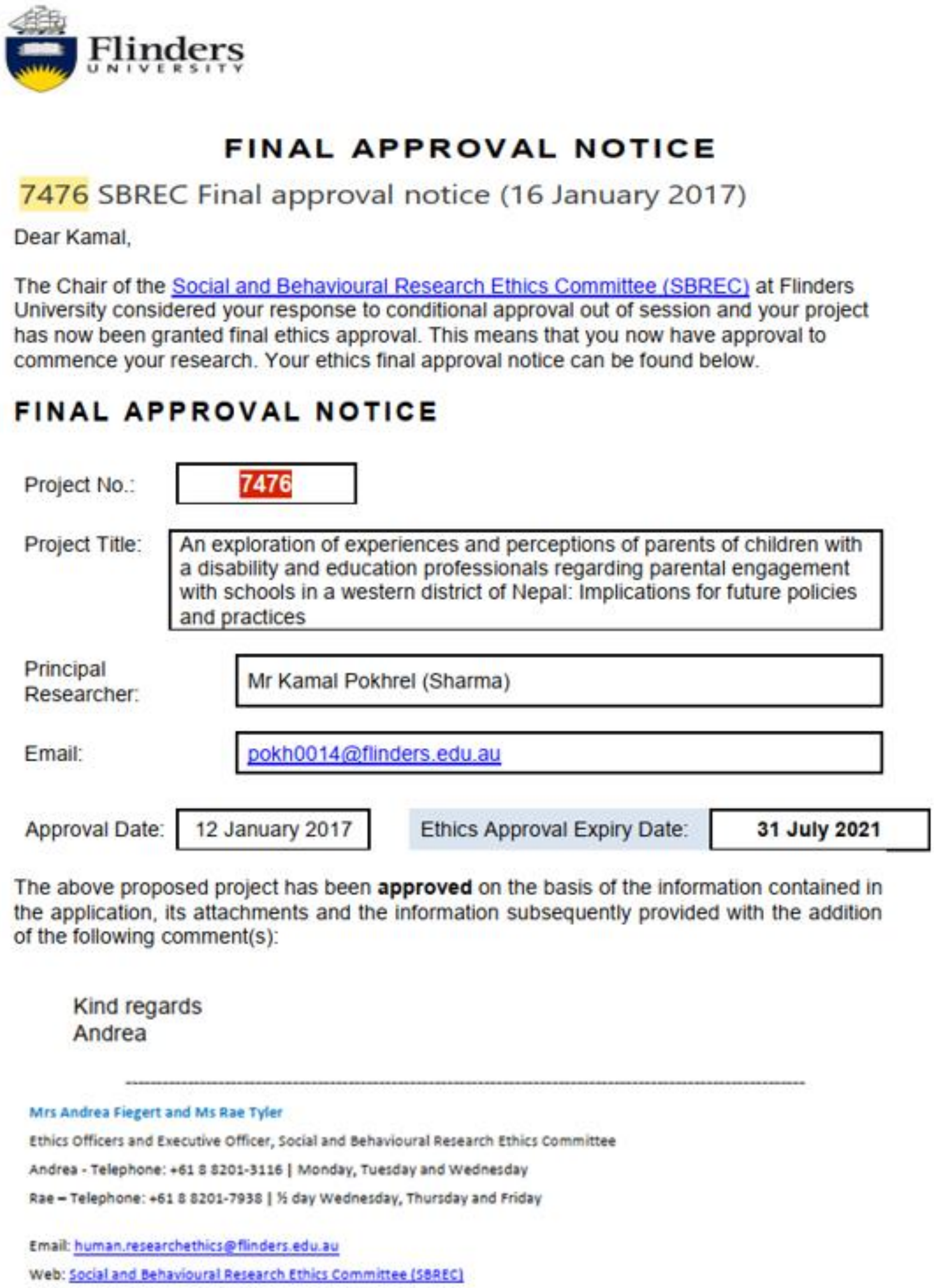
२. यस्तो प्रकारको परिवारलाई तपाईले कसरी वा कस्तो सहायता प्रदान गर्न सक्नु हुन्छ ?

३. यस्ता बाबुआमालाई तपाईको विद्यालयमा सक्रिय सहभागी गराउन के कस्ता सम्भावनाहरु वा उपायहरु छन् ?

४. तपाईंको विचारमा यस्तो परिस्थितिलाई ती बाबुआमाले कसरी लिन्छन होला वा कस्तो मान्छन होला ?

६.. तपाईको विद्यालयमा अभिभावकहरुको उच्च गुणस्तरको सहभागिता सुनिश्चित गर्न तपाई के गर्नुहुन्छ ?

Appendix G: Final ethics approval notice obtained from Flinders University



Flinders
UNIVERSITY

FINAL APPROVAL NOTICE

7476 SBREC Final approval notice (16 January 2017)

Dear Kamal,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

FINAL APPROVAL NOTICE

Project No.:	7476		
Project Title:	An exploration of experiences and perceptions of parents of children with a disability and education professionals regarding parental engagement with schools in a western district of Nepal: Implications for future policies and practices		
Principal Researcher:	Mr Kamal Pokhrel (Sharma)		
Email:	pokh0014@flinders.edu.au		
Approval Date:	12 January 2017	Ethics Approval Expiry Date:	**31 July 2021**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment(s):

Kind regards
Andrea

Mrs Andrea Fiegert and Ms Rae Tyler

Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee

Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday

Rae – Telephone: +61 8 8201-7938 | ½ day Wednesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au

Web: Social and Behavioural Research Ethics Committee (SBREC)

Appendix H: Letter requesting permission to conduct research

Dear Head Teacher,
(Name of the school, and address)

My name is Kamal Prasad Pokhrel (Sharma) and I am a PhD student at the School of Education, Flinders University in Adelaide, South Australia. I am undertaking a research project leading to a production of a thesis or other publications on the subject of experiences and engagement of parents of children with disabilities in Nepal. In this context, I am wishing to listen to stories of up to nine parents about their experiences of their child with a disability and their schooling. I am also wishing to undertake focus groups with the head teachers, teachers, members of school management and parent–teacher associations.

For this, as I will have to access your school and also need to collect publicly available documents that are not accessible online (such as citizen charter, code of conduct, school newsletter or magazines and school development plans); I am hereby seeking your permission to visit to the school and collect the documents mentioned above. I have herewith also attached an information pack comprising introduction letter, information sheet and consent forms. If you require any further information, please do not hesitate to contact me on the address given below. Thank you for your time and I hope you will consider this request positively.

Yours sincerely,
…….

Kamal P Pokhrel (Sharma)
School of Education, Flinders University
Email: pokh0014@flinders.edu.au

To whom it may concern:

I give permission to Kamal Prasad Pokhrel (Sharma) to access the school for his research and also to collect the school documents, as described above.

……… (*Sign and date*) ……….

School's Stamp

Head teacher
(Name and address of the school)

____

Appendix H (Nepali translation)

परिशिष्ट छ : अनुसन्धान कार्य गर्न अनुमतिको लागि अनुरोध पत्र

(क) श्री प्रधानाध्यापकज्यू ।

(विद्यालयको नाम तथा ठेगाना)

प्रस्तुत विषयमा निवेदक म कमल पोखेल फ्लिन्डर्स विश्वविद्यालय, स्कूल अफ एजुकेशन, एडिलेड, दक्षिण अष्ट्रेलियामा विद्यावारिधिको विद्यार्थी हुँ । मैले शोधपत्र तथा अन्य लेख रचना प्रकाशन समेत गर्ने प्रयोजनका लागि नेपालमा अपाङता भएका बालबालिकाको अभिभावकहरूको सहभागिता सम्बन्धमा स्वयम अभिभावक तथा शिक्षा पेशामा संलग्न व्यक्तिहरूको अनुभव र बुझाइ विषयमा अनुसन्धान कार्य गरिरहेको छु । यस सन्दर्भमा म विशेष आवश्यकता भएका विद्यार्थीका अभिभावकहरुको शिक्षामा संलग्नता सम्बन्धमा उनीहरुको अनुभव तथा बुझाइ सुन्न लागि म इच्छुक छु । त्यस्तै यसै विषयमा विद्यालयका प्रधानाध्यापक, शिक्षक, विद्यालय व्यवस्थापन तथा अभिभावक शिक्षक संघका सदस्य विचार र अनुभव थाहा पाउनका लागि लक्षित समूह छलफल गर्न पनि इच्छुक छु ।

यसका लागि मलाई तपाईंको विद्यालयमा आउन पहुँच हुनु पर्ने र विद्यालयले सार्वजनिक गर्न मिल्ने तर अनलाइन उपलब्ध नभएका दस्तावेजहरु (जस्तै नागरिक बडापत्र, आचार संहिता, विद्यालयका मुखपत्र वा परिचय पत्र, स्मारिका, विद्यालय सुधार योजना आदि) समेत संकलन गर्नु पर्ने भएकाले सो को अनुमति प्रदान गरि दिनु का लागि अनुरोध गर्दछु । यसका साथै अनुसन्धानकर्ताको परिचयपत्र, अनुसन्धानसम्बन्धी जानकारी पत्र र मञ्जुरीनामा फारमहरु यसै साथ संलग्न गरेको छु । यस सम्बन्धमा थप जानकारी आवश्यक परेमा तल उल्लेखित ठेगानामा सम्पर्क गर्न सक्नु हुने पनि जानकारी गराउँदछु । यस सन्दर्भमा तपाईंको समयका लागि धन्यबाद छ र साथै यस अनुरोधलाई सकारात्मक रुपमा लिइ दिनु हुने छ भनी आशा गरेको छु ।

भवदीय

....
कमल प्रसाद पोखेल (शर्मा)
स्कूल अफ एजुकेशन फ्लिन्डर्स विश्वविद्यालय
इमेलः pokh0014@flinders.edu.au

विद्यालयको छाप

श्री जो जस संग सम्बन्धित छः

मैले निवेदक कमल प्रसाद पोखेल (शर्मा) लाई वहाँको अनुसन्धान कार्यका सिलसिलामा माथि जनाइए बमोजिम यस विद्यालयमा पहुँच गर्न तथा माथि उल्लेख भए बमोजिमका विद्यालयका दस्तावेजहरु संकलन गर्ने अनुमति प्रदान गरेको छु ।

..... *(दस्तखत तथा मिति)* ....

प्रधानाध्यापक

(विद्यालयको नाम तथा ठेगाना)

....

Appendix I: List of activities undertaken during the research period

a. Two co-authored chapters published

- Henderson, L., Stephenson, H., Bissaker, K., Alexander, V., Dawadi, D., Heath, J., Kupke, S., Pokhrel, K., & Schultz, K. (2016). Being RHD learners in a group supervision model: Collaborating to strengthen individual pursuits. In M. Picard & A. McCulloch (Eds.), *Proceedings of the 12th biennial Quality in Postgraduate Research (QPR) conference* (pp. 113–119). Adelaide, SA: QPR Organising Committee.
- Bissaker, K., Kupke, S., Dawadi, D., Pokhrel, K., Alexander, V., Shearer, J., Stephenson, H., Henderson, L., & Nawab, A. (2019). The power of an effective community in creating networked researchers: Outcomes beyond a thesis. In M. Dollinger (Ed.), *Getting the most out of your doctorate: The importance of supervision, networking and becoming a global academic* (pp. 63–82). Bingley, UK: Emerald.

b. Conference proceeding abstracts approved for presentation and published

- Pokhrel, K. (2016). Decision-making and engagement of parents of children with a disability in relation to their children's school: A narrative case study of parents' experiences in a western district in Nepal. In Book of Abstracts (p. 7), Post Graduate Scholar's Conference (20 June 2016), Flinders University, Adelaide, Australia.
- Pokhrel K. (2017). Engagement of parents of children with disabilities in Nepalese schools: Implications for future policies and practices. In PGS Conference 2017: Abstracts (p. 6), Post Graduate Scholar's Conference (19 June 2017), Flinders University, Adelaide, Australia.
- Pokhrel, K. (2018). Voices and roles of Nepalese parents and their communities in caring for and educating their children with disabilities. In Thinking, Doing, Learning (p. 3). HDR Conference (19 June 2018), Flinders University, Adelaide, Australia.
- Bissaker, K., Dawadi, D., Henderson, L., Kolajo, S., Kupke, S., Nawab, A., Pokhrel, K., Shearer, J., & Stephenson, H. (2018). The relative nature of success in the doctoral journey and the influence of group supervision on candidates' sense of success. Abstract of a co-authored article approved for presentation and published in Quality in postgraduate research (p. 119). Adelaide, South Australia, (April 17–19, 2018). Available http://www.qpr.edu.au/wp-content/uploads/2018/04/QPR_2018_Program.pdf

c. Conferences attended

- June 2017 – A one-day Research in Special Education (RISE) conference with the main theme: Investing in Inclusion: Research to Practice, Flinders University, Adelaide
- June 2018 – Higher Research Degree (HDR) Conference, Flinders University, Adelaide
- April 2018 – A three-day 13th Biennial Quality in Postgraduate Research (QPR) Conference in Adelaide. Conference Theme: Impact, Engagement, and Doctoral Education, Date: 17–19 April 2018, Adelaide, South Australia
- June 2017 – A one-day Post Graduate Scholar's Conference (PGSC), Flinders University, Adelaide
- June 2016 – A one-day Post Graduate Scholar's Conference (PGSC), Flinders University, Adelaide
- Attended several seminars organised by Flinders University, Adelaide, such as Critical theory, Endnote, NVivo session, COMMs course, Introductory Academic Program (IAP) Course, English Language Support Program (ELSP) Course, seminars on mindfulness, grounded theory, partnerships between Flinders and Bologna and so on.

- In addition, attended and contributed to the fortnightly meetings of research higher degree students with activities focusing on article writing, discussion, reading circles, practice/presentation, experience sharing and so on.

d. Presentations

- June 2018 – Higher Degree Research (HDR) Conference, Flinders University, Adelaide (I presented the preliminary findings of the research and sought feedback from peers/colleagues).
- June 2017 – Post Graduate Scholar's Conference (PGSC), Flinders University, Adelaide
- June 2016 – Post Graduate Scholar's Conference (PGSC), Flinders University, Adelaide

e. Future works anticipated relating to this research

- Planning to write two to three peer-reviewed articles as an outcome of this research for relevant journals drawing on the methods and findings of this research related to special education or parental education
- Planning to design a pilot project to initiate collaboration between education and health sectors at the local level, by inviting health professionals and policy makers as well as colleagues in education to work together so that children with disabilities and their parents could be supported in a meaningful way and to tap into the potential of parents with disabilities and other local resources
- Planning to producing a book by reorganising the materials of the thesis (have started researching the skills needed to do this, some resources have been found at these links: http://www.niaspress.dk/files/excerpts/Jackson_extract.pdf; https://www.press.uchicago.edu/Misc/Chicago/288463.html; https://www.mup.com.au/blog/turning-your-thesis-into-a-book).

Appendix J: A brief summary of three events in the follow-up visit

Event one: Visit to a parent's home (Parent 1, Daya)

Daya told us that they had started a small restaurant business in a market near her rented home. Daya's husband had left his previous job as a driver and would support her in the restaurant. During this visit, Leigh wanted to know more about this family from Daya and her husband including several aspects of their son's education. We sat at a table in the open space in front of the restaurant. Daya served us tea. I translated the conversation between Leigh, Gary and this family. Gary helped us record the conversation and also contributed to the conversation. This conversation lasted for 38 minutes. As in her first conversation with me, Daya shared that Rabin has been doing incredibly well in the school, has been smart in his studies and both parents are happy with his progress. Similarly, she also shared the same concerns as previously about Rabin's schooling and education, such as no promotion to higher grades in the school, concerns about his next school, and her desire for him to be admitted to the school at Bhairahawa. I felt this time that Daya had the same worries about her child, even after two years passed since she talked to me. This may be because she did not get any chance to meet the school's authorities during these two years to express her concerns, or her concerns were not addressed even after the school's authorities knew them.

Event two: Visit to a parent's home (Parent 15, Bel Bahadur)

During the follow-up member checking visit in early 2019, I went to Bel Bahadur's home again. I checked in with them about their latest situation. During this time, my supervisor, Leigh, asked Bel Bahadur about how they first time came to know about Padam's disability, what they did to cure him, his education and so on. I translated the conversation for Leigh and this family between English and Nepali. Bel Bahadur also shared with us that there had not been any substantial changes since my last visit. By this time, I also noticed many other people had surrounded us. Maybe they were curious to listen to a conversation with strangers. Before we left his home, some people asked Leigh if she could take Padam to her country for treatment. We had to say 'no' as this was not possible within the scope of our visit.

Event three: Visit to school and its hostel and meeting with focus group participants

During this follow-up visit, Leigh, Gary and I visited School A to meet and share my research findings with a group of head teachers and teachers, who were mostly participants in my focus groups (focus group 1 and 2, Table 3.3) with a view to seek their comments and inputs on the findings. My presentation was followed by Leigh's presentation in which she shared her different individualised interventions to cater for three students with disabilities in Australia. The presentation aimed to offer an insight to the participants on how schools and teachers in Australia design and implement customised and individualised support to children with disabilities. During the presentation, participants were encouraged to ask questions. Gary also participated in the conversation and supported us to take pictures and record the discussion. I translated the discussions between Leigh and Gary and participants, whenever it was necessary.

In this school, we also visited the children's hostel adjacent to the school. There were 9 students in the hostel. Leigh also talked to the aaya and wanted to know about the operational aspects of the hostel. Leigh and Gary were so touched by the situation in this hostel that they offered to buy mattresses, bed covers and pillows for the students. While staying in Kathmandu, before their return to Australia, Leigh, Gary and I worked out options for transferring money to the school. Leigh and Gary then transferred the amount, as estimated by the head teacher, to the school's account from Kathmandu.

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