

The Inclusiveness of Society for Children with Disability in Nepal

A CRITICAL ANALYSIS OF THE CONCEPTUALIZATION OF DISABILITY IN
POLICY AND PRACTICE

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Abstract

Background: Although the recognition of disability issues has increased and evolved in policy and practice in recent years, children with disabilities in Nepal have been shown to continuously experience obstacles in their enjoyment of basic human rights and to their inclusion in society. An inclusive society is considered to be key to social development, promoting equal opportunities and fair participation for everyone in the community.

Objective: In order to enhance understanding of the situation of disabled children in Nepal today, this analysis strives to evaluate how disability policy and practice have been developed and how they justify interventions to the challenges at stake. Critical attention must be paid to the complexities of how disability is embedded in social, cultural, and historical processes. Review of the role and relevance of commonly used concepts, with the focus on the inclusiveness of society, broadens insight into the current discourse on disability.

Methods: This study uses a combination of qualitative research methods to integrate the theoretical conceptualizations of disability with real life experiences from professionals working in the field for disabled children. Firstly, a scoping review provides fundamental background knowledge on disability within the Nepalese context. Secondly, an analysis of the problem representation within disability policy and practice at both the international and national level provides insight in how, why and with what consequences disability has been framed as it is today. Thirdly, interviews with disability experts from Nepal deepen the understanding of the situation for disabled children in Nepal and what implications policy and practice have on the ground.

Results: Discourses on disability in Nepal are formed by the unique and distinctive aspects of context-specific realities that have shaped perspectives and notions on disability. The analyzed policy and practice share ideas based on the social, rights-based approach to disability, but differently construe the concepts in their problem representations. Societal inclusion is recognized by all initiatives representing ideology rather than actual practice.

Conclusion: Even though the social, rights-based approach has been shown to offer new powerful perspectives to tackle the issues faced by disabled children and advances their societal inclusion, substantiations to address disability by a more holistic, integrative approach are strong. To become an effective measure, the concept of inclusiveness of society requires a change from an idealistic desire towards an everyday practice.

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Abbreviations

CBR	Community-based rehabilitation
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CWD	Children with disabilities
DPO	Disabled people's organization
HRW	Human Rights Watch
MDGs	Millennium Development Goals
NGO	Non-governmental organization
PWD	Persons with disabilities
UN	United Nations
UNDESA	United Nations Department of Economic and Social Affairs
UNICEF	United Nations Children's Fund
WHO	World Health Organization
WPR	What's the problem represented to be - Approach

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1 Introduction

An inclusive society is considered to be key to social development, promoting equal opportunities and fair participation for everyone in the community (UNDESA, 2009). This inclusiveness is thought to foster social integration and protect particularly disadvantaged and vulnerable groups. Yet, children with disabilities (CWD) often encounter different forms of exclusion that create barriers to the enjoyment of their basic human rights and to their inclusion in society (UNICEF, 2007). While they have the potential to play meaningful roles in their communities, they are denied access to social services, the chance to attend school, or opportunities for employment later in life (UNICEF, 2013b). Even though they are in great need of healthcare services, they commonly have less access than children without disabilities (Kuper, et al., 2014). Across the world, it has been estimated that around 100 million children under the age of 18 live with disabilities (HRW, 2013). These children need a supporting environment to be able to develop to their utmost capacity.

In Nepal, CWD and their families are confronted with difficult impediments, considering the socio-political context and high level of poverty (Mol et al., 2014). In particular, CWD in low and middle-income countries are likely to face obstacles in transitioning from childhood to adult independence (UNICEF, 2007). They have an increased chance of staying in or facing poverty, malnutrition and poor health. Since the available statistics vary substantially depending on definitions and measures used, estimates of the prevalence of disability in Nepal range from 0.5% to 25%, comprising both disabled children and adults (HRW, 2011). Nonetheless, continuous government and community efforts have changed the situation of CWD for the better. The adaptation of policies on disability issues has increased and the engagement of CWD in schools has improved (Shrestha & Nilsson, 2012). However, the lack of awareness, advocacy and capacity to effectuate policies and regulations still pose a decisive problem to the realization of equity and social justice among the population (Shrestha & Nilsson, 2012). Cornielje (2012) further describes how negative attitudes towards CWD, local resistance to inclusive services or the lack of skills and expertise among families and communities still hinder the inclusiveness of society in Nepal.

1.1 Research Purpose

Considering the previously described conditions for CWD in Nepal, it is valuable to dissect policies and practices that have been created to improve the current situation. This analysis is of importance to conceive how initiatives conceptualize disability and societal inclusion in order to understand recent developments in the disability domain. As Ferguson & Nusbaum (2012, p. 70) describe, a "*growing ambiguity*" characterizes disability claims and

the complex embedding of disability into social, cultural and historical processes therefore requires critical attention. To gain an understanding of the objectives behind current policies and practices helps to identify underlying assumptions that shape the approach to disability. This knowledge provides insight into how concepts of disability and inclusiveness are brought into reality. Both policies and practices, if not necessarily geared to each other, have important implications for each and everyone in the society. This vital link between a theoretical level of ideas and real life experiences of professionals working with disabled children in Nepal is central to this research.

1.2 Research Scope

This research project was conducted in cooperation with the Karuna Foundation Nepal, an organization that has been engaged in projects for Nepalese people with disability since 2007 (Karuna Foundation, 2014a). While administrative and organizational issues are dealt with in an office in the Netherlands, the initiatives for disabled people are implemented in several communities in Nepal. The guiding vision is *"a world in which each individual, with or without disabilities, has equal access to good quality health care, can lead a dignified life, and can participate as much as possible in community life"* (Karuna Foundation, 2014a; p. 1). Specific objectives focus on the quality of life of disabled children. The objectives entail definite reduction of birth defects and disabilities among children alongside fundamental empowerment and capacity building strategies targeting system-wide problems. As part of the organization's effort to improve the lives of disabled children, this study contributes to a greater understanding of societal inclusion and its significance for disability issues in Nepal. This research takes an analytical look at one of the central programs of the Karuna Foundation, the Inspire2Care program, and incorporates its analysis into broader political and societal realities.

1.3 Research Objectives

The aim of this study is to explore the concept of disability so as to enhance understanding of the situation of disabled children in Nepal. In particular, this research aims to broaden the insight into the current discourse on disability by providing an in-depth investigation of important underlying paradigms, focusing on the inclusiveness of society. The interest lies in the identification of how disability policy and practice have been framed and upheld. Therefore, problem representations of selected policy documents are assessed and subsequently compared to those used on the ground. This analysis demonstrates how policies and practices have been developed and how they justify interventions to the challenges at stake.

1.4 Research Question

The main research question for this study is:

How is inclusiveness of society for disabled children conceptualized within current international and national disability policy and practice in Nepal?

To illustrate the steps taken in the study to answer this research question, the following sub-questions were developed:

a) What issues of disability are identified and how are they represented in the policy and practice under study?

b) What approaches to disability are suggested in the policy and practice under study?

c) What are the effects of the problem framing in the disability policy and practice under study?

d) How do these problem representations in policy and practice relate to expert perspectives on the situation on the ground?

e) What is the potential for policy and practice to contribute to the inclusiveness of society for disabled children in Nepal?

1.5 Thesis Structure

Firstly, this paper depicts the theoretical background, exploring the underlying approach to this disability study. Secondly, the methodology is explained with a detailed description of: the scoping review, the analysis of policies and practices, and additional expert interviews. Thirdly, the results are presented. Background information is given on important cultural, historical and epidemiological dimensions of disability in Nepal. Following this, identified policies and practices are analyzed and complemented with expert opinions. Finally, a discussion and conclusion close the thesis.

2 Theoretical Background

To analyze the conceptualization of disability and examine the meaning of inclusiveness of society in current policies and practices in Nepal, this study draws on the "What's the Problem Represented to Be?" (WPR) – approach developed by Carol Bacchi in 1999 (Bacchi, 2009). As illustrated in Table 1, the WPR approach is directed by six questions to accomplish a thorough analysis. This approach represents a practical framework to investigate problem representations in social and political debates (Bletsas & Beasley, 2012). While Bacchi's intended use for the WPR approach is policy analysis, the approach can also be used to examine other materials such as economic decision-making or cultural

materials. The WPR approach emphasizes the importance of concepts as they are used and defined and constantly changed or re-imagined. Bacchi (2012) concludes that these dynamics shape what is considered to be a problem and thus what needs to be done to solve it.

Two key premises direct Bacchi’s reasoning: a) “we are governed through problematizations”, b) “we need to study problematizations (through analyzing the problem representations they contain), rather than ‘problems’.” (Bacchi, 2009, p. xiii). Policies and other documents often contain implicit problem representations and thus, it is of great interest and importance to investigate the problematizing process. Social problems are framed and constituted within assumptions often based on the cultural or historical context (Bacchi, 2009). Bletsas & Beasley (2012) state further how this approach highlights “the politics of research” (p. 2), as any study or report is shaped by political ideas with social effects and cannot remain neutral. This framing is central to both governing processes in policy making, and the argumentations in social or cultural debates. Therefore, Bacchi (2009) argues that it is essential to “interrogate the kinds of problems that are presumed to exist and how these are thought about” (p. xiii). She presents a critical interrogation tool for public debates, which has been described by Bletsas & Beasley (2012) as “one of the most innovative analytical frameworks developed in recent times” (p. 1).

Table 1: The WPR Approach to Policy Analysis

What’s the problem represented to be? - Approach
1. What’s the problem represented to be in a specific policy?
2. What presuppositions or assumptions underlie this representation of the problem?
3. How has this representation of the problem come about?
4. What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?
5. What effects are produced by this representation of the problem?
6. How/where has this representation of the problem been produced, disseminated and defended? How could it be questioned, disrupted and replaced?

Source: Bacchi (2009)

The WPR approach is inspired by post-structural theory and, in many regards, based on Foucauldian thinking (Mackinnon, 2012). The theory of Michel Foucault, a French philosopher (1926 – 1984) and influential social theorist, follows a genealogical paradigm characterized by taking a historical perspective on phenomena (Krieger & Crahan, 2001). Krieger and Crahan (2001) state that Foucault identified a close interrelation between

discourse and practice. This connection between opinion and action results from strong mechanisms of power, which constructs the life of each individual. In line with this, Mackinnon (2012) states that Bacchi's approach begins with the assumption that everything has an impact on social matters, and that socio-historical context shapes the direction these impacts take. Coveney and Putland (2012) further hold that looking at what the problem is represented to be is to look for "*how things ought to be*" (p. 74). These ideas are based on post-structuralism, which Bacchi (2009) defines as "*an intellectual tradition that emphasizes fluidity and contestation in social thought and relations, and the politics involved in assigning meaning.*" (p. 277). Bacchi (2009) emphasizes how policies organize everything in certain ways, which often entails the effect that populations are categorized and divided into groups. This theory is about constructed realities and their changing meaning over time and space. Bacchi (2009) brings in a social constructionist perspective, observing that these realities ought to be questioned. She encourages investigation of conceptualizations' origins, and the effects they can have on daily life.

Full understanding of the WPR approach requires in-depth knowledge about the six constituent questions, and what each tries to investigate. The first question clarifies what "*implicit problem*" is represented in the text of interest (Bacchi, 2009, p. 2). Proposed approaches and interventions within each document are taken to reveal the underlying problem representation. Bacchi (2009, p. 3) describes this approach as "*working backwards*" to identify the complexity that some policies are based on, as it is possible to find multiple problem representations, including some which may be contradictory. The second question explores those ideas, which substantiate the represented problems (Bacchi, 2009). Some knowledge is taken for granted and results in presuppositions or assumptions upon which argumentations are built. Bacchi (2009, p. 5) refers to "*deep-seated cultural values – a kind of social unconscious*" which shapes problem representation. This task requires close examination of the language used in each document. Critical importance is placed on specific language used because wording creates meaning to text. Question 3 emphasizes how problem representations are susceptible to change and influenced by broader historical processes (Bacchi, 2012). Hence, the context of time and space is key to understanding the manifestation of problem representations.

The subsequent questions continue with critical analysis of the implications of problem representations. The objective of the fourth question is to shift focus towards silenced issues and perspectives within the chosen representations of the problem (Bacchi, 2009). Possible gaps or limitations are carefully scrutinized to examine what fails to be problematized. Bacchi (2009) argues that conceptualizations require simplifications, which constrain policies within implied limits. The fifth question assesses the effects and

implications certain problem representations have (Bacchi, 2009). Three effects are under scrutiny: (a) discursive effects: the effects of silencing on framing an issue and the implied limits on what can be thought and said about it; (b) subjectification effects: the effects on created positions and social relations of people in society, and; (c) lived effects: the effects on materials for people to live their lives (Bacchi, 2009). The sixth question highlights the means through which dominant problem representations are produced and challenges potential harm, which may result from the established policy claims (Bacchi, 2012). This question further directs attention to the complexity of discourses, and the way they are legitimized to reach their target audience.

2.1 Conceptualizations of Disability

The disability discourse is thought to be strongly influenced by conceptualizations made in academia, policy, practice and civil society (Gurung, 2009). Disability has been approached by a variety of theories and over time there have been changing perspectives on how disability can be problematized (Ronoh, Gaillard, & Marlowe, 2015). By way of example, Norad (2012) describes a main shift from the predominant medical model towards the now common social approach to disability. The medical model focuses on the biological features, which defined interventions and perspectives, whereas the social model views disabled children in their social context. While disabled children were seen as dependent and research concentrated solely on the role of the impairment inducing the disability, new approaches enforce participatory methods which highlight other factors that play an important role in shaping disability (Watson, 2012). The subsequent development of a rights-based approach led to important changes in how to address issues faced by CWD. The rights-based approach supports recognition of all children as full members of their families, communities and societies, and thus their full inclusion (UNICEF, 2013a). The children's participation and integration is essential to this process. Therefore, Watson (2012) argues that to approach disability comprehensively, the social model should not be limited to analysis of social barriers, but be open to include political, cultural and environmental factors, too. Additionally, Emens (2012) discusses how attitudes influence behavior towards CWD, which may result in barriers towards them. She states that the provision of an insightful perspective from disabled children on their situation can change these attitudes, which are often negatively framed.

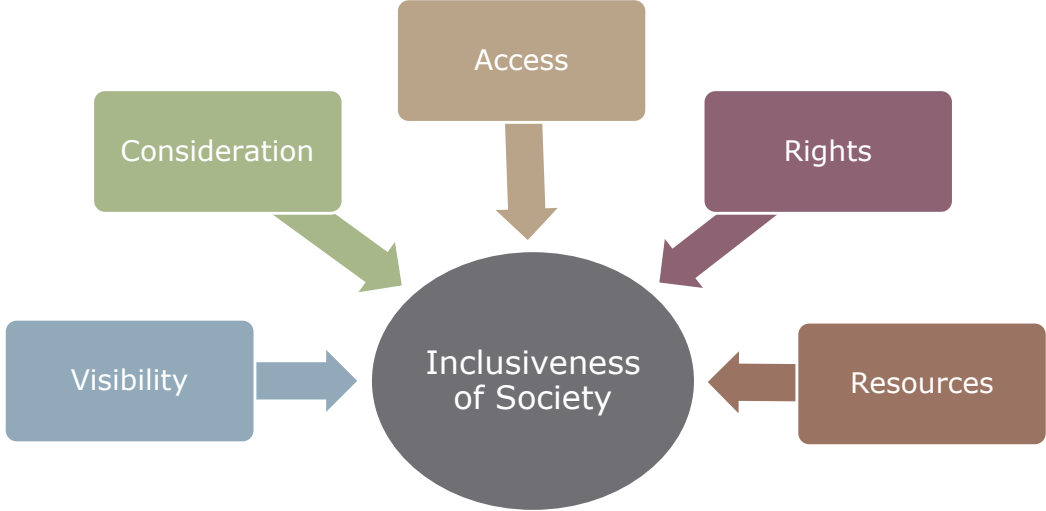
Yet, there is no international agreement on how to define and approach disability. A commonly used definition is the one from the International Classification of Functioning, Disability and Health (ICF), in which disability is described as an *"umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual and that individual's contextual factors"*

(WHO, 2015b). This definition resembles the social model of disability. Although CWD can experience problems directly due to their impairment, primarily it is societal realities that are disabling by creating pervasive barriers. These barriers are diverse, with examples including limited support from families and communities to integrate the children in schools, cultural practices or leisure time activities. According to the World Health Organization (WHO), disability comprises various states of impairments, which can be diverse in nature (WHO, 2011). In research different types of disabilities are distinguished: visible or non-visible, temporary or permanent, painful or inconsequential disabilities (WHO, 2015b). Human Rights Watch (HRW, 2011) distinguishes, for instance, between intellectual, learning, psychosocial and developmental disability. Interestingly, not all people with disabilities (PWD) perceive themselves to be unhealthy (WHO, 2011). Hence, disability has been described as multidimensional and considered to be constructed by the interaction between any physical or psychological impairment to health with the social and environmental conditions in which the person lives (WHO, 2011). Disability in this sense, is assumed to be a preventable, alterable construction, which can be reduced by adaption or complete curing.

2.2 Conceptualization of Societal Inclusion

Societal inclusion can be defined as *"a process by which efforts are made to ensure equal opportunities for all, regardless of their background, so that they can achieve their full potential in life"* (UNDESA, 2009, p. 3). The inclusiveness of society is considered to be fundamental to overcome various obstacles for CWD. As outlined by UNICEF (2013c, p. 11): *"adopting an approach grounded in respect for the rights, aspirations and potential of all children can reduce the vulnerability of children with disabilities to discrimination, exclusion and abuse"*. Therefore, societal inclusion builds upon the social integration of individuals, which promotes the participation of all people in social, economic, cultural and political spheres based on their fundamental human rights. Inclusive societies are characterized by principles such as equality, solidarity and justice (UNDESA, 2009). Therefore, it is assumed that inclusiveness of society requires a holistic strategy to be achieved. The United Nations Department of Economic and Social Affairs (UNDESA, 2009) describes social inclusion as a multi-dimensional process aimed at lowering economic, social and cultural boundaries and outlines five important dimensions that should be considered as vital steps to the inclusiveness of society, as illustrated in Figure 1. These explanations are by no means to be understood as universal. Inclusiveness of society is a concept with myriad interpretations. However, this framework provides a useful starting point to understand how wide the scope of its conceptualization can be.

Figure 1: Five Dimensions of an Inclusive Society



Source: created on the basis of UNDESA (2009)

According to the framework, visibility is crucial for CWD to be included in the society. They need to be noticed and recognized; the identification of CWD and awareness among communities is essential for fulfilling this step. Secondly, consideration plays an important role with respect to local policy making and societal structures. If marginalized groups are not considered, their needs and concerns will not be accounted for. Consideration implies that in any sphere of life CWD can participate and articulate their specific needs. By way of example, involving them in the design and operation of healthcare services, school education or community facilities can contribute to their better inclusion and quality of life (WHO, 2011). Thirdly, access to social interaction is essential for CWD. Participation in any social or cultural event supports the child’s development and its integration in the society. This further includes the possibility for social mobility and social capital (UNDESA, 2009). Social mobility requires, for example, accessible infrastructures such as roads and transportation systems. Social capital relates to how CWD are able to build up social networks with their peers and their community. Fourthly, rights to education and healthcare, as well as freedom from discrimination and stigmatization, increase the social inclusion in society. This means that they should have full enjoyment of their rights meaning equal access to participate with other children in school, play and sporting. They are entitled to the same rights as other children in their community and have the possibility to develop to their utmost potential (HRW, 2011). Finally, resources are important for full participation in all aspects of societal activities. Even though children might have the rights, they might not have the means to assume their rights. Consequently, inclusiveness of society can only be achieved if all dimensions are embraced. The dimensions are interlinked and one may not be achieved without the other.

Considering these insights in the disability discourse and the idea of societal inclusion, the importance of analyzing the conceptualizations of disability made in the context of Nepal becomes evident. To understand how disability is defined and constructed in policy and practice helps to identify the approach taken towards this issue in the country and what the effects may be in a particular context. The particularities of approaches are context specific and have vital implications on CWD in the Nepalese society. If these are understood and taken into account for interventions, the capability to create structural change for these children will increase.

3 Methodology

The posed research question is addressed by means of qualitative research methods. Qualitative research is particularly suitable for in-depth evaluation of complex issues (Ruane, 2006). This method broadens the understanding of underlying phenomena and provides a holistic approach to capture multifactorial situations (Creswell, 2009). Since concepts like disability or societal inclusion continuously evolve, qualitative research is appropriate to provide detailed information on how these conceptualizations take place. A combination of a scoping review, policy analysis and expert interviews was chosen to allow triangulation of findings, and integration of political and social perspectives into one analysis (Harden, 2010). In the following chapter, a detailed explanation of these complementary methods is given.

3.1 The Scoping Review

Scoping reviews are useful to gain background knowledge on the evidence of a specific topic or field of interest (Davis, Drey & Gould, 2009). This information is not only necessary to provide fundamental information about the current situation for disabled children in Nepal, but is further useful to support analysis claims in the subsequent policy and practice investigation. This scoping review intends to gather evidence on the inclusiveness of society for CWD in Nepal. As shown in Appendix 1, a modification of the Cochrane 'checklist for developing a search strategy' was applied to conduct the review (Naumann, 2007). The search terms were determined according to the Cochrane checklist and included: disability, impairment, handicap, inclusion, exclusion, mainstreaming, children, adolescents, youth, and Nepal, among others. Different spellings, synonyms, appropriate truncations and the Boolean operators 'AND' and 'OR' were taken into account to achieve a thorough search. Relevant documents were identified in recommended databases from Maastricht University, namely the Advanced Search of the university itself, SocINDEX and CINAHL (see Appendix 1). Additional publications or grey literature were identified by hand searching of reference lists and an internet search engine so as not to miss important

documents. As presented in Table 2, papers were included if they addressed aspects of societal inclusion related to the disability discourse in the Nepalese context. Identified articles which primarily focused on disability, but showed great relevance to the background of the topic, were included likewise. Exclusion criteria referred to the specific deviation from the research topic, such as explicit mention of another country, age range or population group of interest. Based on the previously presented theoretical background, a directed, qualitative content analysis was used to extract relevant information from the texts (Hsieh & Shannon, 2005). The guiding questions of Bacchi’s approach to analyze problem representations were transformed into categories which were then used for coding (see Table 3).

Table 2: Inclusion and Exclusion Criteria for the Scoping Review Search

Strategy

Inclusion Criteria	
International, national and local initiatives on social inclusion or social exclusion of children with disability in Nepal.	This includes any document which addresses the inclusiveness of society for children with disability in Nepal.
All documents must be in English and be fully accessible online and published between 2008-2015	The timespan has been chosen due to the history of Nepal. Since 2008, Nepal has been officially a Federal Democratic Republic after long-lasting conflicts.
Exclusion Criteria	
Documents which do not address children specifically	This study focuses specifically on children with disability. Due to the fact that children with disability may have other needs than adults with disability, those documents which address adults specifically will not be relevant for this analysis. However, documents addressing disability in general or the transition phase from a child to become an adult will be included.
Documents which do not mention disability or inclusiveness	Initiatives need to focus on disability or inclusiveness, preferentially both disability and inclusiveness.
Documents that do not target Nepal	Nepal is the local context of interest, therefore this study will only include initiatives targeting any region or area within Nepal. However, general background studies on disability and inclusiveness that are relevant for the Nepalese context will be considered as well.
Documents in Nepalese	Due to the inability of the researcher to speak Nepalese any documents in the local language have to be excluded.

Table 3: Categories for the Content Analysis based on the WPR-Approach

Question	Categories
1. What's the problem represented to be in a specific policy?	Problem representation: definitions, explanations or reasons for disability/societal inclusion
2. What presuppositions or assumptions underlie this representation of the problem?	Presuppositions/Assumptions: binaries, key concepts, categories for disability/societal inclusion
3. How has this representation of the problem come about?	Genealogy: developments, decisions, processes, events in the discourse on disability/societal inclusion
4. What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?	Silencing: criticism, gaps, limitations, simplifications in the discourse on disability/societal inclusion
5. What effects are produced by this representation of the problem?	Effects: perspectives, opinions on disability/societal inclusion; situation, conditions, behavior, positions, relations for disabled children and the society they live in
6. How/where has this representation of the problem been produced, disseminated and defended? How could it be questioned, disrupted and replaced?	Origination: explanations, elaborations on the disability discourse

3.2 The Policy and Practice Analysis

The analysis of policy and practice in Nepal which contribute to the well-being of disabled children is the central part of this research. Thereby, the importance of policy and practice on achieving future objectives for development is recognized. However, this study does not intend to analyze policy processes or their effectiveness, but rather the focus is on the underlying problem representation in these initiatives. This approach is based on the assumption that policy and practice making is constructed within certain paradigms and belief systems (Thissen & Walker, 2013). These conceptual models determine what is being valued and how society is structured and understood. As Thissen & Walker (2013) state these "*conceptual models are fairly limited and should be under constant scrutiny and subject to revision*" (p. 12). Therefore, these conceptualizations are investigated to analyze how disability and inclusiveness have been problematized in the Nepalese context and to what extent this influences the aspiration for an inclusive society for CWD. As presented in Appendix 2, relevant policy documents were identified through a systematic search of the WHO MINDbank database and the government website of the Ministry of Health and Population in Nepal. For the sake of this research's scope, one international and one

national policy document were included respectively. First, the WHO MINDbank database was searched by using the keyword 'disability' and in a second step, the search was narrowed down to United Nation (UN) and WHO resolutions or declarations on disability and country-specific resources of Nepal. The Nepalese government website returned nothing using the keyword 'disability'. Therefore, the publication section on policies and strategies was reviewed. Table 4 presents the established inclusion and exclusion criteria for the eligibility process, which ultimately identified the international policy “Draft WHO global disability action plan 2014 – 2021: Better health for all people with disability”, and the national policy “Nepal’s National Policy and Plan of Action on Disability 2006”. These policies were the most topical documents on the subject matter that could be found. As previously indicated, the Inspire2Care program from the Karuna Foundation was chosen for the practice analysis because this project represents one important example of practice seeking to contribute to societal inclusion for CWD. By means of the WPR approach, the underlying problem definition within existing policy documents was assessed. Therefore, the following questions were used to lead analysis:

1. *What is the problem represented to be in the document?*
2. *What presuppositions or assumptions underlie this representation of the problem?*
3. *How has this representation of the problem come about?*
4. *What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?*
5. *What effects are produced by this representation of the problem?*
6. *How/where has this representation of the problem been produced, disseminated and defended? How could it be questioned, disrupted and replaced?*

Table 4: Inclusion and Exclusion Criteria for the Policy and Practice Analysis

Inclusion Criteria	
International and national policies or practices addressing social inclusion or exclusion of children with disability.	This includes any decision, plans and actions that have been taken by global or international organizations and national, either governmental or non-governmental, public or private, institutions having an impact on the inclusiveness of society for children with disability in Nepal. This impact may be direct (documents that address Nepal specifically) or indirect (documents with a global/worldwide scope). It is recognized that policies may focus on either inclusiveness or disability and therefore, both types of policies will be included.

All documents must be in English and be fully accessible online	Documents in Nepalese cannot be included because the researcher is not familiar with the local language
Exclusion Criteria	
Documents which do not address children specifically	This study focuses specifically on children with disability. Due to the fact that children with disability may have other needs than adults with disability, those documents which do not address children specifically will not be relevant for this analysis. However, documents addressing the transition period from a child to become an adult will be included.
Documents which do not mention disability or inclusiveness	It is desirable that those documents which focus on either disability or inclusiveness at least mention the relationship between the two phenomena.
Documents that do not define disability or their target population	Since it is an essential goal to evaluate the underlying problem definition within the identified policies, it is a necessity that the policies mention their definition of disability or their target population.
Documents that do not target South-East Asia	Disability is an issue which needs to be dealt with within the context. Therefore, it is important that policies are included that target at least those regions which are applicable to the Nepalese local setting.
Documents in Nepalese	Due to the inability of the researcher to speak Nepalese. Any documents in the local language have to be excluded.
Documents that are outdated	Only topical policies will be taken into account, if there are any new policies published that built upon or refer to another policy of the same kind, only the newest ones will be analyzed

3.3 The Expert Interviews

Lastly, interviews were conducted to gather detailed information from experts in the field, to inform the existing research findings and to deepen the understanding of societal inclusion within the Nepalese context. Snowball sampling was used to identify potential participants, taking the professional network of the Karuna Foundation as a starting point (Browne, 2005). Potential participants were contacted via mail and invited to take part in an interview via Skype or telephone. Strict selection criteria were applied, so that only experts with experience working in Nepal were qualified for the interviews. They must have worked either for a governmental or non-governmental organization (NGO) that engages for CWD. Academic experts with knowledge on policy research within the Nepalese context or with background in health science/public health/social sciences in Nepal were included as well. In total, six interviews were conducted with experts currently working in

international NGOs, being representatives of or advocates for disabled children (see Table 5). These interviews lasted between 30 and 60 minutes each. As illustrated in Appendix 3, these interviews were conducted as semi-structured interviews based on a prepared interview guide, so that data could be easily compared later on (Polit & Beck, 2010). This design was chosen to leave room for the respondent in answering the questions to ensure themes would not be missed out. To seek greater understanding of societal inclusion of disabled children in Nepal, the questions primarily sought information on the situation for Nepalese CWD. Personal experiences and opinions on disability and societal inclusion were investigated to analyze the experts' conceptualization of these issues. Furthermore, general knowledge about policies and practices on disability in Nepal was important to get insight into the meaning of the social and political discourse in Nepal. These interviews were recorded with verbal consent of the participants. Subsequent transcription of the interviews after each conversation reduced potential reporting bias. The expert interviews were analyzed by using a conventional, qualitative content analysis to further explore the concept of inclusiveness of society within the specific context of Nepal (Hsieh & Shannon, 2005).

Table 5: Detailed Information about Conducted Interviews

Interviewee	Method type	Interview length	Date
Representative in a Nepalese Disabled People's Organization (female)	Skype (due to internet connection both calling and chatting)	46 min	03.07.2015
Program director of an international NGO in Nepal (male)	Skype	37 min	14.07.2015
Community Based Rehabilitation expert working in an INGO (female)	Skype	58 min	22.07.2015
Program director of an international NGO in Nepal (male)	Skype	33 min	31.07.2015
Advocate for disabled people through journalism and work in NGOs (male)	Telephone	37 min	31.07.2015
Program director of an international NGO in Nepal (male)	Skype	53 min	05.08.2015

3.4 Ethical Considerations

The expert interviewees were asked to participate on a voluntary basis. They were informed about the researcher's background and interest, as a Master student in Global Health at Maastricht University. Data collection was based on the principle of confidentiality. In addition, during the whole research process, in particular referring to the data analysis, the participants' information was handled anonymously. Throughout the research process, differences between the researcher's origin and the participants' cultural, religious or other social sensitivities and traditions were taken into account and respected. Moreover, it is acknowledged that an analysis of conceptualizations is influenced by the researcher's understandings and values (Jepsen, 2014). Despite the utmost effort being made to achieve complete objectivity, each interpretation in the data analysis process can be effected by cultural or historical context which has shaped the researcher's experiences and presuppositions. Reflection on contexts itself is rarely simply descriptive, but rather an interpretative task (Bacchi, 2009).

4 Results

The following analysis is structured according to the previously presented research steps and presents relevant information about the discourse on the inclusiveness of society for CWD in Nepal. First, basic background information is given to provide insight into contextual factors influencing the issues under study. Second, an in-depth evaluation of selected disability policy and practice is undertaken. Finally, perspectives and experiences from the field complete the analysis with topical expert insights.

4.1 Disability in the Nepalese Context

While landlocked between two rapidly developing nations, India to the South and China to the North, Nepal remains one of the poorest countries in the world (USAID, 2015). Nepal's political instability due to a long-lasting violent conflict resulted in a slow transition towards rehabilitation and peace. It was only in 2008 that Nepal was constitutionally declared a federal republican state with democratic procedures and new administrative powers (Gurung, 2009). Since then progress in socioeconomic, educational and health issues has been made (WB, 2015). However, Shrestha et al. (2009) indicate differing levels of well-being between the ecological zones in Nepal. While the hilly area in the middle of the country has the highest Human Development Index, the plain region in the South and the mountain area in the North are gradually less developed (Pradhan & Shrestha, 2005). In 2012, the total population was estimated to be more than 27.4 million with an average

annual population growth rate of 1.2 % between 2010 to 2015 (UN, 2014). According to the UN (2014), 34.7 % of these people were children aged 0 – 14 years in 2013. Nepal has an enormous variety of cultures, religions and races (Gurung, 2009). Shrestha et al. (2009) state that more than 100 diverse caste and ethnic groups, as well as more than 100 languages and dialects, exist in Nepal. Because these various groups create important social distinctions, the Nepalese society has been characterized as having a highly hierarchical structure.

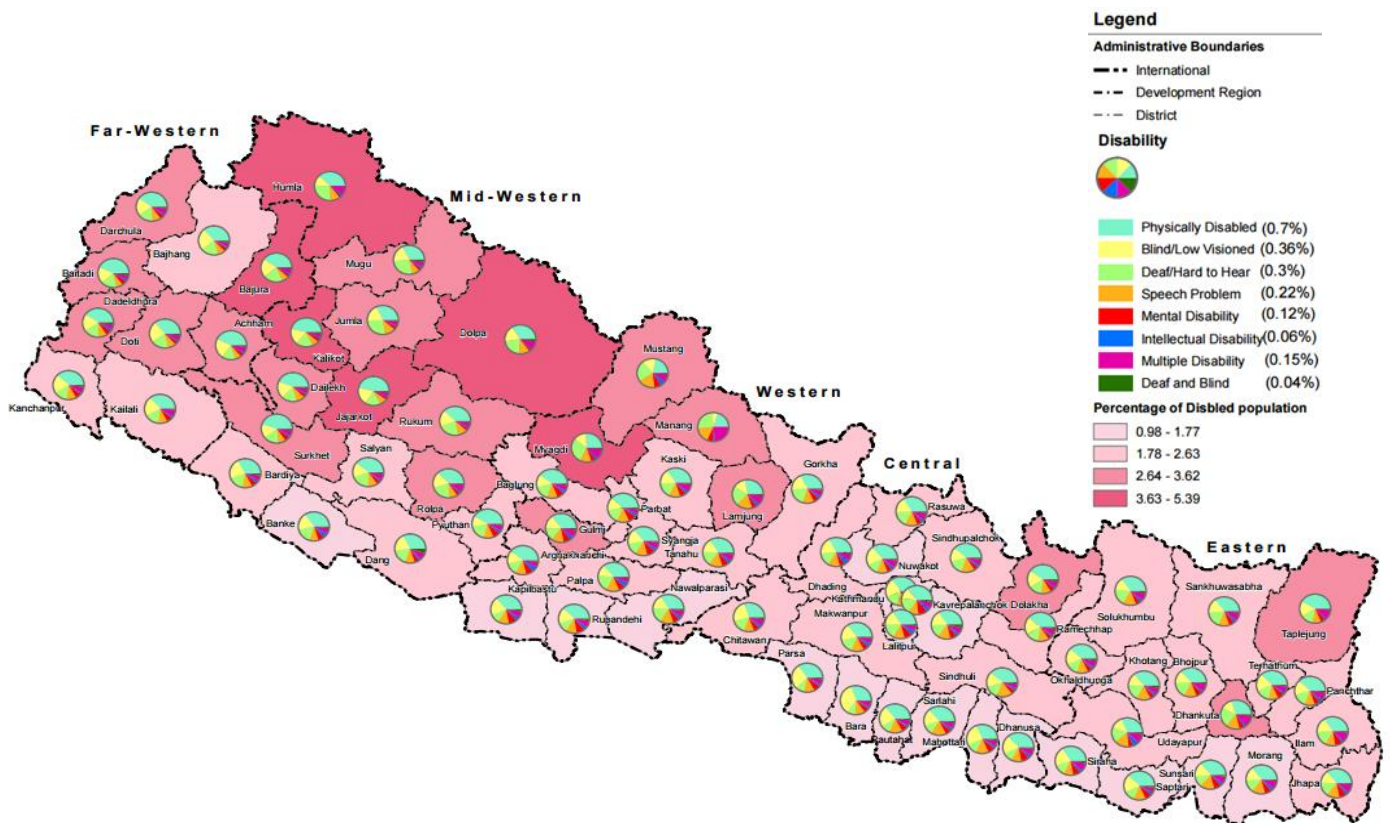
4.1.1 Epidemiology of Childhood Disability in Nepal

The number of disabled children living in Nepal is difficult to determine. Subedi (2012) argues that the reliability of the monitoring mechanisms is questionable and remains inconsistent and inaccurate. The complexity of disability and issues in definition and terminology create enormous challenges to measurement and comparison of disability (Strong & Brown, 2011). According to a study in 2001, the prevalence of disability in the population was approximately 1.63 %, of which around 200,000 children were counted (National Planning Commission/UNICEF/New Era, 2001). The national census in 2011 did not provide specific data on children (aged 0 – 16), but presented estimations of disability in the total population, as illustrated in Figure 2. Disability is recognized in Nepal as existing in eight distinct categories: physical disability, visual disability, hearing disability, deaf-blindness, voice and speech disability, mental disability, intellectual disability and multiple disabilities (UN, 2013). It is striking that the prevalence of disability appears to gradually increase from east to west and south to north of the country, in which the topography is predominantly hilly and remote. Disability is assumed to be more prevalent among women, older people and children who all face barriers in accessing services in healthcare, education, transport or employment (HRW, 2013). Moreover, physical disability represents the most common form among disabled persons in Nepal. Intellectual disability, deaf-blindness and mental disability are less frequent in the population. It is difficult to determine if these estimations reflect the current situation for children in Nepal. However, it is suggested that it is possible to draw a parallel between the different age groups because numerous disabilities occur by birth and last a whole life.

Vaccine-preventable diseases, such as polio, measles and meningitis are associated with impairments among children in Nepal (HRW, 2011). These conditions can result in physical or learning inabilities. Malnutrition and poor access to health care are associated with other abnormalities in early childhood. Post-conflict consequences and poor reproductive health are also considered to trigger impairments among children in Nepal (Tamashiro, 2010). For example, Morley & Kohrt (2013) draw attention to child soldiers who took part in the country's civil war and have shown a high burden of functional impairment, depression and

post-traumatic disorders. A range of these represented risk factors are preventable (Mahesh, Yoshitaka, Junsuke, & Suraj, 2008).

Figure 2: Disabled Population in Nepal



Source: UN (2013)

Numerous children with an impairment are hindered in their development of essential life skills and participation in school, which is a huge obstacle in reaching their full potential (WHO, 2012). Children with an impairment are two to three times more likely to not attend school (UNESCO, 2008). Poverty has been identified as a main reason for children to suffer from disability and constraints within their environments, and is in turn often a consequence of disability (HRW, 2013, de Silva de Alwis, 2009). The relationship between disability and poverty is complex and determined by several factors, such as insufficient access in transport, healthcare, education or nutrition (Shrestha, Shrestha & Deepak, 2009). Moreover, contextual factors, such as conflict, war or stressful environments, can increase the vicious cycle between poverty and disability. Due to their condition, disabled children are vulnerable to various forms of discrimination, such as violence, exploitation or social exclusion (Singal & Muthukrishna, 2014). Violence against CWD occurs approximately 1.7 times more often compared to violence against children without disabilities (UNICEF, 2005). Human trafficking and sexual abuse are other examples of the

negative consequences disabled children may be confronted with in Nepal (de Silva de Alwis, 2009). Another issue is persistent neglect of disabled children by some families or communities. Hendricks et al. (2014) affirm how attitudes and cultural beliefs can result in exclusion and stigmatization of Nepalese CWD.

4.1.2 International and National Legal Frameworks for Childhood Disability in Nepal

One important international treaty for disabled children is the Convention on the Rights of the Child (CRC), which promotes the equal enjoyment of human rights for children with or without disabilities (UN General Assembly, 1989). Since 2008 the International Convention on the Rights of Persons with Disabilities (CRPD) promotes further the full and equal enjoyment of all human rights and fundamental freedoms by disabled persons, including CWD (HRW, 2013, UN General Assembly, 2007). Lord and Stein (2008) hold that the CRPD is a milestone for CWD around the world because this convention provides great opportunity to influence domestic law and initiate policy reform.

Despite the fact that Nepal ratified both the CRC and CRPD, it has been claimed that several barriers still prevent children with impairments from full inclusion and integration in society (Reilly, 2010; WHO, 2011). These barriers are diverse and include inadequate policies, negative attitudes, lack of service provision and inadequate funding (Cornielje, 2012; Shreshta & Shreshta, 2014). Gurung (2009) is critical that there are no effective policies in Nepal that include marginalized communities in the planning processes and implementation stages, such as in the case of the Millennium Development Goals (MDGs). She argues the MDGs had no meaningful impact on the life of disabled and poor children. Lack of political commitment and strong domestic policies generated by the long-lasting conflict hindered successful implementation. Moreover, political oppression and economic exploitation due to the hierarchical structure of society and other forms of marginalization contribute to increased social exclusion (Langford & Bhattarai, 2011). Since the 1990s, as Albert and Harrison (2008) hold, conditions have started to change due to continuous lobbying by disability advocates. Tanaka (2011) describes the important role of NGOs in Nepal in these developments who began to integrate disability issues into their work internationally and nationally. Nonetheless, resources are limited in Nepal, so there are only a number of specialized educational and healthcare services for children who have, for example, a visual impairment (Eisenman, et al., 2014; Lohani, Singh & Lohani, 2010). Mahesh et al. (2008) describe how children with low vision capacity are often treated in the same way as completely blind children because trained personnel and proper devices are insufficient or non-existent. Another study, which focused on youth employment in

Nepal, pointed out that disadvantaged groups, including disabled adolescents, face problems in finding an employment due to high levels of social discrimination, and lack of access to information or lack of good education (ILO, 2008).

Nevertheless, the inclusiveness of society in Nepal is an issue that has been given considerable attention in academia, development work and policy making (Gurung, 2009). Gurung (2009) declares that although the Nepalese government committed itself to incorporation of marginalized populations into mainstream programs, the government failed to actually implement those. For example, the Poverty Reduction Strategy Program for Nepal identifies human development and social inclusion as central to its key objectives, but strategic actions to achieve these goals were never realized. However, there were also positive examples on the progress of social inclusion in Nepal. For example, Bhutta et al. (2008) identified the effectiveness of a participatory intervention for women to support them during pregnancy by identifying potential problems and strategies to address them. Women were more likely to have hygienic care and regular check-ups during their pregnancy, reducing the risk of their child developing a disability. Furthermore, the adoption of community-based rehabilitation (CBR) practices have changed the way Nepali perceive disability and have increased inclusive and respectful treatment of disabled children (Velema, Ebenso, & Fuzikawa, 2008; Handicap International, 2011).

In summary, the delineation of given conditions in Nepal for CWD has provided essential information on contextual factors relevant for disability policy and practice. Sociopolitical and cultural particularities characterize Nepal as a country that faces obstacles to achieve good health and well-being for society. This context is fundamental to capture the conceptualization of disability and societal inclusion to their whole extent. As Bacchi (2009) holds, governance takes place within specific historical, cultural and geographical contexts which are fundamental to the policies put in place. In global health policy making these ideas help to analyze the meaning of policies and the purpose they serve.

4.2 Disability Policy and Practice in Nepal

Both international and national policy making determine the role each governing body takes to tackle a specific issue and what underlying assumptions are made. Policy and practice are closely interlinked and should ideally shape one another. Since policy seeks to structure and shape practice, it is important that policies which are made on a higher level suits actions on the ground. As previously stated, the WPR approach to policy analysis aims to understand how problematizations shape policy making and the implications for society (Bacchi, 2009). Below, the WPR approach is applied on the Nepalese "National Policy and Plan of Action on Disability 2006" and the "Draft WHO global disability action plan 2014 –

2021: Better health for all people with disability” which direct initiatives for CWD in Nepal. The approach is also applied on one example of practice, namely the “Inspire2Care Project” from the Karuna Foundation Nepal.

4.2.1 Draft WHO Global Disability Action Plan 2014 – 2021

In 2013 the WHO Executive Board stressed the importance of disability and called for further action by submitting the draft “WHO global disability action plan 2014 – 2021: Better health for all people with disabilities”. One year later the 67th World Health Assembly adopted the action plan, which was further developed in cooperation with other national and international stakeholders and based on recommendations of the WHO and the World Bank “World report on disability”. Three objectives are outlined: *“(1) to remove barriers and improve access to health services and programs, (2) to strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services and community-based rehabilitation, (3) to strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services”* (WHO, 2014). The plan aims to contribute *“to improve health, well-being and human rights for persons with disabilities”* (p. 2) and is aligned with the CRPD (WHO, 2014).

The WHO integrates both a biomedical and social paradigm into the concept of disability by adopting the definition of the ICF (WHO, 2014, p. 3). This leads to the combined consideration of personal and societal aspects to address disability. Accordingly, PWD include each individual with either a disability by birth or through any other condition that limits their functioning. On the basis of the CRPD it is stressed that disabled persons are hindered to equally and fully participate in society (UN General Assembly, 2007). Children and youth are not prominently mentioned, but included throughout the policy document in the broad terms ‘people’ or ‘persons’ with disabilities (WHO, 2014, p. 3). This description declares that nobody is excluded from being likely to experience disability and therefore the concept is seen as universal. Hence, it is not about putting an end to disability per se, rather to reduce or remove the disadvantages associated with it. Disability is represented to be a problem of exclusion and lack of access. PWD experience barriers that result in poorer health outcomes, lower educational achievements, less economic participation, higher rates of poverty and an increased dependency, and restricted participation (WHO & the WB, 2011). These barriers are avoidable and the WHO global disability action plan is hoping to change this situation for PWD.

To support the argument that disability is an emerging issue three dimensions are explored further. Firstly, disability is described as a global public health issue because this condition can affect anyone in any population independent from geographical context and disability

can be a risk factor for other health problems. The impact of globalization on disability has been and will be of increasing importance, is complex and can be both positive and negative. Secondly, disability is a human rights issue as PWD often undergo fundamental violations of their rights. They have difficulties accessing their rights, such as receiving education or health care. The human rights debate offers an effective tool to prevent discrimination and stigmatization and makes it a legal obligation to act for PWD. Thirdly, disability is a development priority since disability is strongly associated with poverty and is more prevalent in low resource settings. These three dimensions provide a powerful justification for the action plan and create liability among not only global health stakeholders, but also among human rights delegates and development organizations. Hence, the improved situation for PWD is a means to broader global development goals; it is *"the way forward, a disability-inclusive development agenda towards 2015 and beyond"* (WHO, 2014).

The action plan presupposes the dichotomous concept of being disabled/non-disabled for its explanations. For example, the 4.6 times higher risk of experiencing sexual violence is compared between disabled children and their *"non-disabled peers"* (WHO, 2014, p. 9). This presupposition creates a hierarchical distinction between the two groups. Those with a disability experience greater health risks than those without. Hence, disabled populations are presented as disproportionately affected victims who need special attention in assuring their well-being. These assumptions are connected to the common change in the approach to disability towards the consideration of social dimensions (Nordic Consulting Group, 2012). The disproportionately affected group of disabled persons is not responsible for their disability, but rather the environment they live in is. As a consequence, the surrounding stakeholders are asked to engage in removing barriers and prevent PWD from being disadvantaged, and thus, the action plan calls upon several organizations, service providers, civil society, academia and communities to accomplish a multi-sectorial commitment (WHO, 2014, p. 7).

In the WHO's global disability action plan, social inclusion is mentioned with respect to community activities meaning to *"support independent living and full inclusion in the community"* (WHO, 2014, p. 21). Mainstreaming and attitude change are fundamental strategies to overcome challenges (WHO, 2014). Additionally, the action plan refers to inclusion in the context of healthcare. The specific actions comprise the *"inclusion of people with disability in public health policy"*, *"inclusion in the health sector"* and *"inclusion or access to mainstream health care services"* (WHO, 2014, p. 12, 13). The concept of inclusion signifies mandatory equality in prevention, treatment and rehabilitation efforts. PWD need to have the same opportunities and participation in all health areas. The action

plan returns to the concept of 'health for all', which was historically seen as an important step towards global health (WHO, 2015a). In 1978, the Alma Ata Declaration was agreed to achieve health for all by managing primary healthcare for everyone. By taking up this concept after more than 30 years, its use appears as an acknowledgement that PWD have been excluded from this process and require a separate attempt to be included. Accordingly, Tomlinson, et al. (2009, p. 1857) argue that "*health of people with disability cannot be achieved in isolation*"; a sustainable improvement requires broader alterations in social realities.

The way in which disability is represented as an issue in the action plan has certain implications for people. Although inclusiveness and environmental aspects are targeted by the WHO action plan, the concrete strategies entail mostly the increase in service delivery. This seems to revive traditional attempts to disability. Albert & Harrison (2008) state that "*despite their use of the language of human rights and the social model, in practice most (...) continue responding to disability essentially as a question of rehabilitation*" (p. 6). This can have a subjectification effect on PWD because the perception that they are recipients of charity or social welfare may not be overcome. The continuous use of words including "*assistive*", "*enabling*" or "*ensure services*" lead to these perceptions (WHO, 2014, p. 16). Nevertheless, the policy does integrate the objective to have representative functions of organizations of PWD in decision-making processes (WHO, 2014, p. 6). The emphasis on the added value of the views and opinions of PWD is recognized to help achieve the aim of empowering them. Tomlinson et al. (2009) further stress the need to research the ways that are effective in delivering the proposed interventions to PWD. They emphasize the analysis of a wide spectrum of factors that contribute to the disability experience to be able to deliver "*dignified and acceptable*" solutions (Tomlinson, et al., 2009, p. 1861).

In summary, the WHO action plan provides an international framework for disability, which is determined by the conceptualization of disability as resulting from preventable barriers. As a leader in global health, the WHO's global disability action plan emphasizes health improvements for PWD by expanding service delivery. However, PWD could not only benefit from better access to health and health care, but also progress in other sectors such as education, infrastructure and labor, which would positively impact their health status. Promotion of the inclusion of disability ought to be fostered not only in health discourse, but also other important areas of life. The action plan represents an important step to increase the health and well-being of disabled persons, including CWD.

4.2.2 Nepalese National Policy and Plan of Action on Disability 2006

The "National Policy and Plan of Action on Disability 2006" represents a response to regional developments in disability policy elaborated by the Extended Asian and Pacific Decade of Disabled Persons in 2003 – 2012 and the Biwako Millennium Framework of Action adopted in 2002 by the Economic and Social Commission for Asia and the Pacific (UN ESCAP, 2002; Nepal Government, 2006). In Nepal the first concrete disability legislation, the Disabled Protection and Welfare Act, was developed in 1980s/ early 1990s providing benefits and special services in education, health, employment, transport and social welfare to PWD (MEND, n.d.). In the coming years, several legal acts were adopted, including the Social Welfare Act in 1992, the Child Protection Act in 1992 and the Education Act in 2000, which contributed to increased provisions for PWD. And yet, stating that disabled persons' needs still have not been met, the goal of the national policy in 2006 is to establish an "*inclusive, obstacle free and rights-based society for people with disability*" (Nepal Government, 2006, p. 6).

Disability is constituted to be a problem of the fulfillment of people's rights, as shown by the statement "*a situation exists where the expected achievements have not been made in the establishment and development of the rights of people with disabilities*" (Nepal Government, 2006, p. 7). PWD are denied their human rights in areas of education, health, labor, infrastructure, communications and other services (Nepal Government, 2006). Disabled persons are largely underestimated, discriminated and excluded from social, economic or cultural spheres. For instance, the education system and teachers are not adequately prepared with the consequence that "*children with multiple disability have not received the opportunity to study in a convenient and free manner*" (Nepal Government, 2006, p. 51). They are not provided with personalized, fostering education. Furthermore, the capability of PWD to work and to be valuable for companies' productivity is underestimated, so that training, recruitment and hiring of disabled persons are lacking. Similarly, accessibility to public buildings and public places is inadequate because those areas have not been constructed with respect to disabled friendly infrastructure (Nepal Government, 2006).

To understand the underlying assumptions made by this problem representation, a reflection on the rights-based approach to disability becomes useful. Quinn & Degener (2002) elucidate the underlying values that shape the human rights instrument in the context of disability: "*The inestimable dignity of each and every human being, the concept of autonomy or self-determination that demands that the person be placed at the center of all decisions affecting him/her, the inherent equality of all regardless of difference, and the ethic of solidarity that requires society to sustain the freedom of the person with*

appropriate social supports." (p. 1). This human rights perspective implicates that disabled persons are holders of rights that entitle them to be treated equally and without discrimination. They are as much a part of society as everyone else and need to be protected. The responsibility to protect them lies primarily with the nation state, which is the leading authority to implement human rights in practice. In line with this, the action plan states that it is "[the] nation's obligation to follow and carry out international and regional treaties and declarations promulgated for the rights of people with disability" (Nepal Government, 2006, p. 7). National institutions, such as the Ministry for Women, Children and Social Welfare or the Disabled Service National Coordination Committee, cooperate with NGOs, development agencies and civil society to create "equal opportunity, participation and access" (Nepal Government, 2006, p. 14).

The binary negative discrimination/ positive discrimination underpins the rights-based approach, with "affirmative action" taken as a means to greater equity between disabled and non-disabled persons (Nepal Government, 2006, p. 8). Affirmative action or positive discrimination describes initiatives that have the intention to reduce inequalities and disadvantages that have been experienced by minority groups, such as disabled persons (Harris & White, 2013). Even though the concept has a positive purpose, affirmative action has been criticized due to potential mismatch between the given position and the actual capability of the favored person and a possible negative impact on others, particularly in schools or universities (Fullinwider, 2009). Others, however, defend the concept on the grounds of social justice and the compensation for an unfair disadvantage (Fullinwider, 2009).

Moreover, "democratic government" and "good governance" are particular expressions that are used as significant keywords in the Nepalese action plan (Nepalese Government, 2006, p. 13). These terms provide the policy with important underlying principles that can also be identified as core values of the UN or, so to say, Western government practices (UN, 2015). The rights-based approach is embedded in both these concepts. Democracy is said to be "based on the freely expressed will of people and closely linked to the rule of law and exercise of human rights and fundamental freedoms" (UN, 2015). Democratic governing seeks to create political processes that are inclusive and responsive to people's choices, needs and aspirations. Good governance, as defined by the UN, is characterized by "participation", "rule of law", "transparency", "responsiveness", "consensus oriented", "equity and inclusiveness", "effectiveness and efficiency" and "accountability" (Sheng, n. d.). Good governance represents an idealistic ambition for contemporary decision-making processes and stresses particularly the integration of vulnerable populations' interest (Sheng, n.d.). Both these key terms support the government's plan to reverse the situation

of CWD “*who are prevented from the mainstream of country’s development*” (Nepalese Government, 2006, p. 12). The Nepalese action plan in 2006 is also aligned with other international and regional developments in the context of disability. Direct references are made, for instance, to the United Nation’s Standard Rules on the Equalization of Opportunities for Persons with Disabilities or the Asian and Pacific Decade of Disabled Persons policies (Nepalese Government, 2006, e.g. p. 22). The Nepalese government holds that the plan is part of greater development efforts, namely the “*task of poverty alleviation and social inclusion*” (Nepalese Government, 2006, p. 13). In line with this, the promotion of international and regional assistance expansion is part of the planned actions to increase the resources for effective programs. As a consequence, the impression of a relationship of dependency between Nepal and international organizations arises and the assumption is generated that Nepal has scarce resources and low government capacities to enforce their planned reforms. On the contrary, the concession to have a low resource setting and to incorporate the support from external sources advances the options for faster and greater development.

Taking a closer look, the policy plan purports to include the concept of inclusiveness of society. Social inclusion is stated to be an overall objective and is connected to expressions like “*social empowerment*” or “*mainstream of development*” (Nepalese Government, 2006, p. 6, 13). Empowerment can be related to the concept of power and can refer to either the process, or the outcome whereby people gain more control over their lives (Sadan, 2004). Empowerment can be further applied to “*overcoming the direct and indirect obstacles of power which are responsible for the ongoing disempowerment*” (Sadan, 2004, p. 97). Hence, empowerment is linked to removing those barriers that create obstacles for disabled persons to live a life as they desire. Empowerment is about enhancing control and independence for them. Mainstreaming is interrelated with this notion because mainstreaming can be seen as a method to promote social inclusion by addressing the barriers that exclude PWD (Jones & Webster, 2006). This concept stresses the importance of equality and inclusion of persons with or without a disability likewise in any planned action, policy or program (Commission for Social Development, 2008). For instance, the Nepalese government tries to ensure the mainstreaming by “*including activities for protection of the rights of people with disability and development through their participation*” (Nepalese Government, 2006, p. 30). However, the policy does not consider explicitly the complexity of disability. Disability can be of different nature - temporary or permanently, physically or mentally - and thus, the feasibility to remove barriers for PWD can be differently challenging (WHO, 2011).

The common shift from the medical model to the social approach to disability, which has been predominantly defended by Western research projects, is obviously held by the national plan of action (Buckingham, 2011). The social approach is emphasized by the proposed actions, which purely focus on amendments in the environment of disabled persons. Education provision, disability-friendly construction or specific cultural and entertainment programs are some of the propositions (Nepalese Government, 2006, p. 8, 9). While these concrete service provisions are important steps to create better living conditions for PWD, the disabled persons themselves fade into the background. This may have a subjectification effect on disabled persons because they are framed as recipients of special services and affirmative action. The use of the social model can result in division within society because the ones who are not disabled are blamed for creating disability. Social exclusion could therefore be seen as constructed by these notions due to the understanding of "*dividing practices*" (Bacchi, 2009).

Another important aspect that has been silenced in the policy, is the cultural diversity and its impact on societal structure in Nepal. Culture shapes how CWD are treated and perceived in society and leads to increased difficulties in dealing with disability in some communities (UNICEF, 2013a). This silencing results in significant omissions in action taken for disability. They fail to recognize potential conflicts that may arise due to cultural particularities (Thomas & Thomas, 1998). Because Nepalese communities tend to be affected by their religion, ethnicity or race, attitude change and community-based programs may require certain adaptations to be effective. Although the ideals behind the caste system were made illegal in Nepal, it is said to still have negative influence on the Nepalese society by reinforcing discrimination and social stratification (Pyakuryal & Suvedi, 2000). How these conditions shape notions and beliefs on disability issues is important in establishing successful interventions.

Overall, the national plan on disability in Nepal is aligned with the dominant human-rights based approach to disability. The influence of international and regional notions of disability is persistent throughout the document. Since the plan was developed before the WHO action plan, it could not be seen in how far the national policy is aligned with the international one. Still, another question arises in how far the policy has been adapted to the local context in which Nepalese CWD live in. The silencing of cultural dimensions is a noticeable characteristic of the policy, and yet, the actual significance of the plan can be only assessed in its implementation.

4.2.3 Inspire2Care Program of the Karuna Foundation

Karuna Foundation Nepal has been engaged in projects for people with disability since 2007 (Karuna Foundation, n.d.). In the intervening years different initiatives have been implemented to alter the situation of disabled children in Nepal for the better. One central program is the 'Inspire2Care' program which addresses the need to empower communities and vulnerable groups to develop their own capacity to claim their right to participate in the society as every other person does (Karuna Foundation, 2014a) The program was launched in 2011, firstly implemented in two districts, Sunsari and Rasuwa in Nepal. The implementation is effected within government structures by means of the integration of all disability-related actors. The Inspire2Care project is a CBR-based program promoting community ownership and the full participation of CWD and their organizations (Karuna Foundation, 2013). This project is based on multisectoral collaboration to engage all important stakeholders. The aim is to "*improve the quality of life of 2000 children with disability*" and simultaneously decrease the incidence of disabilities due to birth defects (Karuna Foundation, 2013). As indicated in Figure 3, the Inspire2Care model comprises both prevention-related activities and CBR strategies (Vaughan, 2015). These actions target inclusively primary, secondary and tertiary prevention of disability. Firstly, mother and child care is improved by implementing screening and awareness activities and promoting pregnancy registration and pregnancy care. Secondly, the project endeavors to identify individuals with disabilities and further develops the management of their rehabilitation. For example, children's participation and social inclusion is strengthened by self-help groups and inclusive child clubs. Other operational areas include promotion for equal rights for people with a disability and fostering attitude change towards them.

Figure 3: Operation Areas of the Inspire2Care Model



Source: Karuna Foundation (2014b)

The Karuna Foundation represents the problem of disability as grounded in local structures, referring to the existing attitudes and commitment in families and communities. The assessment of local resources and practices is central to the project processes (Karuna Foundation, n.d.). According to the readiness protocol of the Inspire2Care project, change readiness was defined as *“having the right conditions and resources in place to support the change process, having a clear vision and objectives for the intended change, having the motivation and attitudes to engage with the change and make it work and having the right policy (entrepreneurial principles/stopping policy) in place”* (Karuna Foundation, n.d., p. 1). Hence, willingness and capability are important requirements to successfully implement disability projects in communities. Furthermore, it is stated that *“attitude of the people is very crucial for successful implementation”* and insights in the *“practices of the community regarding community development”* deliver understanding of the fundamental community structure (Karuna Foundation, n.d., p.1). Negative attitudes towards disabled persons are associated with discrimination and stigmatization (WHO, 2010). How disabled people are handled is not the same way as others are treated who do not have a disability.

The concept of the Inspire2Care program assumes that local structures generate barriers for the well-being of disabled children. Therefore, improvement of existing health systems and the empowerment of communities and vulnerable groups are means to increase capacity for disabled children to claim their rights. The binary responsible/irresponsible

illustrates the focus of the project. CWD are not held responsible for their situation, but rather the community or family they live in. An important concept the Karuna Foundation is using is the CBR framework. CBR aims at *“enhancing the quality of life for people with disabilities and their families, meeting basic needs, and ensuring inclusion and participation”* (WHO, 2010). This approach relates to the action plan on disability of the WHO, which developed important CBR guidelines in 2010 and integrates those into disability policies (Madden et al., 2014). This framework dates back to the Conference on Primary Health Care in 1978 (WHO, 2010). During that time, the embedding of disability into mythological and religious beliefs was common. In some traditional societies these views are still present today. Therefore, the involvement of the community is perceived as enhancing a more *“inclusive, realistic and sustainable”* development (WHO, 2010, p. 21). Morley and Kohrt (2013) point out that social capital in the form of community support, as well as from peers and family, is essential to prevent CWD from disability induced disadvantages. These ideas support a bottom-up approach in which everyone in the society is held accountable for existing structural barriers for CWD.

The problem representation is based on the tedious process needed to achieve attitude change and sustainable development. As Cornielje (2012) states, negative attitudes persist in Nepalese communities. In contrast, Maudslay (2014) holds that traditional opinions often coexist with other perceptions on disability. She points out that, on the one hand, Nepali may still be exposed to the strong belief that children become disabled due to sins of a past life; on the other hand, some families with a disabled child tend to provide biomedical explanations for their child’s disability. Hence, the situation of disabled children in Nepal is at risk of oversimplification and should be approached carefully by also not assuming negative perceptions per se as implied by the Karuna Foundation’s problem representation. Sometimes it is not the attitude that needs to be changed, but other local structures, such as financial resources or the infrastructure which limit disabled children in their enjoyment of a good quality of life. Low resource settings may lack the means to implement suggested objectives. This has the lived effect for communities to be responsible to provide these resources. Since they are often already living with scarce resources, this may become an obstacle in setting up sustainable projects. The Karuna Foundation therefore addresses capacity building, which has the discursive effect putting the discussion into the development paradigm. Since Nepal is one of the poorest countries in the world, inclusion of the development discourse opens up new means for decreasing negative conditions for disabled children. For instance, the development discourse promotes the eradication of poverty and achievement of primary education inclusively for disabled children, even

though disability was not included as a specific objective in the MDGs from the start (Mattioli, 2008; Griffiths, Mannan, & MacLachlan, 2009).

To conclude, the Karuna Foundation has shown how to adapt international ideas on the ground and how to create bottom-up, long-term solutions for disabled children. The approach can be compared to the analyzed international and national policy, which both seemed to be further away from the local realities in Nepal. While the Inspire2Care program addresses disabled children directly, both policies direct their actions towards all disabled persons, including CWD. The focus of the Inspire2Care project on attitude change and local commitment and integration differed decisively from the problem representations of the analyzed policies.

4.3 Expert Perspectives on Children's Disability in Nepal

"We are trying to make inclusiveness in each and every activity. In the village from the initial day. And when we go to the village to steer our project we invite all the persons with disabilities as well as other persons of the community like political leaders, social leaders, government representatives, school teachers; we do not only talk with the children or person with disability but we also equally pay focus on other parts of the society. Why? Because we consider that the issue of disability is not only with the person with disability." (Program director of an international NGO in Nepal)

Despite the ambiguity of the concept of societal inclusion for disabled children, the interview respondents formulated clear conceptions. They distinguished several elements that are relevant for societal inclusion. For the respondents inclusiveness meant that CWD have equal opportunities and rights to enjoy a life in dignity, respect and confidence. Non-discrimination was a central concept and was especially applied to health and education issues. Moreover, opportunity to be involved in decision-making and general participation in any community activity was emphasized. To get a deeper insight into these topical notions on societal inclusion and its realization, the following sections comprise summaries of the statements made by the interviewed experts which were structured according to identified subject areas.

4.3.1 The Situation for Disabled Children in Nepal

*"Children with disability are still very much marginalized and discriminated."
(Representative for disabled people in Nepal)*

Interview respondents stated that CWD still face discrimination. They identified various issues regarding the access to education. For instance, the accessibility for children is problematic due to the school distance and structure. Disabled children lack the facilities and assistance to be able to attend school education and even if they may have, for

instance, a wheelchair, the school remains inaccessible for them because of missing ramps and other disability-friendly constructions. Some schools do not accept CWD at all. Even if children complete their first level of school education, they face enormous obstacles in proceeding to higher education. Another issue that was raised by some interviewees was the lack of trained professionals to cope with the situation in school. Respondents argued that parents and teachers feel burdened taking care of the children with special needs. Furthermore, the curriculum is not made suitable for disabled children and they do not receive individualized assistance if they are blind or have a hearing impairment. Similar conditions were described for health facilities. Families cannot afford to pay for their child's special health care needs, so that children miss out on early diagnosis and intervention. As a consequence, preventable aggravations of the situation progress and put children at a greater risk for becoming disabled. By way of example, simple eye or ear tests could prevent children from going blind or deaf as a result of complications.

4.3.2 The Complexity of Engaging Stakeholders

"Without the support of the parents and community we cannot carry out the project in the local area." (Program Director for an international NGO in Nepal)

Interview participants elaborated on different challenges that they experience in everyday work. There are a variety of different agencies engaged in the disability sector: international and national NGOs, disabled people's organizations (DPOs), governmental organizations, specialized organizations (blind organization or injury sport association) or generalized organizations. These agencies have different mandates and do not all work together or cooperate with each other. In some cases there is a clash of interests between the government officials, policy makers and advocacy organizations or NGOs who are all trying to improve the situation for CWD, but have different approaches and areas of focus. Therefore, the collaboration takes time and it is difficult to reach consensus. One reason for this is the distinguished understanding and attitude among government authorities and other NGOs. There seems to be a gap between the demand from those organizations and that what the government does supply. Organizations are very limited in their resources and are dependent on funding. The need for continuous campaigns to allocate resources to CWD is an influencing problem. Hence, the social and financial support and strong commitment from communities and families becomes central to creation of successful interventions for CWD.

4.3.3 The Gap between Policy and Practice

"In countries like Nepal plans are developed, but the implementation is (...) more important" (Program director of an international NGO in Nepal)

Respondents claimed that there is a discrepancy between the policies made by the government and corresponding actions on the ground. The main issue was stated to be weak implementation, but also a general lack of political commitment and lack of policies. Although current policies provide structures such as different committees at district and village level, such as the Village Disability Rehabilitation Committee, these committees do not function properly. For instance, some appointed district members do not attend meetings with the consequence that the implementation of policies fails. Moreover, these committees should have at least one representative disabled person, so that they can raise their issues and take influence in each of these structures. Even though the government has also ratified international chis, such as the CRC, the situation for Nepalese children remains poor. The developed national plan on disability in 2006 was also criticized due to huge implementation issues. While there was no revision after five years as proposed, the revision process started in 2015 to establish a new plan for 2016 in collaboration with several disability agencies. Respondents elucidated that the actions posed in the national plan disability in 2006 are not mandatory, but provide guidelines for actions and create opportunities for organizations to demand funding and programs from the government. During the revision process, NGOs were called upon to present their problems in their entirety, so that the government would become more sensitive to the issues. Organizations are limited in their actions and they require “*long patience*” and “*devotion*” to be engaged in the disability sector in Nepal. Government capacity also seems to be insufficient as another interviewee claimed that the responsibility of the government to monitor and delegate responsibility to other agencies needs to be more effective. The interviewee alleged that the government requires commitment, human resources and management to provide competent governance.

4.3.4 The Heterogeneity of Perceptions, Beliefs and Attitudes

“Community perception is totally changed.” (Program director of an international NGO in Nepal)

Respondents stated that the perceptions in communities towards disability had changed greatly in recent years. They elaborated that the belief that disability is “*the force of god*” was an issue of the past. Parents find their disabled children capable of doing tasks which can be done by children without a disability, too. They have greater respect and acceptance of the child’s condition and consider the possibility of rehabilitation and treatment. By way of example, one expert talked about parents who visit their children in hospital care, whereas this was not common in the past. In addition, increased peer support and greater sensitivity among CWD was delineated and substantiated by increased awareness among teachers and community members and the establishment of inclusive child clubs in which

both disabled children and children without a disability take part. Another interesting aspect of this issue was an observed difference between attitudes in rural and urban areas of Nepal. Interviewees elucidated how disabled children in urban areas are mostly hidden by their family, whereas families from rural areas deal with the disability more openly.

"The own family (...), they don't want to invest for their disabled children as they do for their other normal child that is also there" (Representative for disabled people in Nepal)

Nepalese communities were described as very conservative with a strong belief system. Accordingly, the belief that having disabled children is a sin from the previous life was stressed to be still present in Nepalese communities. An attitude change was therefore perceived as vital to realize problem solutions for disabled children. Respondents held that disabled persons have to be involved in decision-making processes. Currently, some political leaders assume that their actions consider disability, so that they do not bother to invite PWD to their discussions; others even do not feel responsible at all.

4.3.5 The Process towards Societal Inclusion in Nepal

"I am not saying that everything has happened in this situation, but (...) I am observing that change has started." (Program director of an international NGO in Nepal)

Interviewees observed significant, positive changes in the Nepalese disability movement in recent years. Increased resource allocation by the government was exemplified. Recently, the government had started to create inclusive education by having teachers trained and by creating disability-friendly buildings. Special resource centers were established that provide further information on CBR and other disability issues. Overall, more attention was given to disability. However, respondents criticized that these measures were not comprehensive enough. For instance, there are still not enough teachers aware about the issues of disability, so that children do not receive appropriate education. The limited resources of organizations also restrict their provision of training. Even if parents demand training, they can only provide training to some of them. Supporting structure were positively emphasized, including the female community health volunteers who provide great capacity to increase awareness and support families. They are further helpful for providing early diagnosis and interventions. Some NGOs stay in the background and engage in lobbying and advocating for more resource allocation for disabled children in the communities. Although change was noticed in the communities as well, respondents stressed that participation of disabled children in community activities is not happening as desired. Awareness levels are increasing, but the pace of this development is very slow.

"If the other parts of the community including persons with disability would realize the problem of these groups and they invest their resources to make a change in the life of the children with disability, take their time, society will reach an ideal situation and every person can get benefit of that development" (Program director of an international NGO in Nepal)

Empowerment was pointed out to be vital to better the lives of disabled children because they are not sensible of their potential to lead a dignified life. They have to raise their demand and claim their rights. In so doing, it is very important to create meaningful participation, such as the involvement in decision-making processes for health or school facilities. The responsibility to empower CWD was ascribed explicitly to the community. Interviewees claimed that the community has the powerful capability to impart knowledge of rights and opportunities to disabled children. It is inevitable that community members without disabilities take the lead in changing conditions. For example, the realization of a disability-friendly environment is not only beneficial for PWD, but also for all other community members, because empowerment of all community members can bring constructive development to society. To achieve this, participatory action was suggested to provide sustainable sensitization of all stakeholders. The own identification and involvement with disability practice was seen as part of a greater "*civilization process*" of the community. This change could only come from within, so that the integration from the start of any initiative is central to successful development. To facilitate this process, information provision to both persons with and without disabilities and support for making consolidations between stakeholders were contended.

To sum up, the interviewed experts have highlighted various issues in approaching disability among children in Nepal. Structural aspects within and between institutions were pointed out to result in incisive barriers towards CWD. Although participants observed positive change in political and societal development, slowness and incongruity of these two processes were stressed. These insights into real life experiences are valuable to assess in how far policy and practice have been constructed in line with actual problems in society and disability practice.

4.4 Disability Policy and Practice in Review

In conclusion, investigating both policy and practice on disability issues in Nepal manifests the relevance of inclusiveness of society within the problematization of disability. Societal inclusion has shown to be an issue for experts in the field as well as policy makers. With that said, both policy and practice have taken up rights-based ideas and the social model of disability, highlighting societal factors to induce disability. Despite these commonalities

between disability policy and practice in Nepal, the differing problem representations of disability within the international, national and local initiatives are striking. The WHO problematizes non-accessible, exclusive services, the Nepalese government stresses denied rights and the Karuna Foundation considers restrictive structures as fundamental to the problematization of disability. As explained in the findings, these ways, in which disability is represented, have different effects on disabled children; what is held problematic, what is proposed to be done about their situation, and what is thought to be needed to change.

5 Discussion

The presented results have touched upon a variety of elements that affect how disability and societal inclusion are framed and perceived. The existing problem representations in policy and practice have been shown to have commonalities, but also differ in certain aspects with distinctive effects on CWD and the societies they live in. Perspectives from experts working on disability issues in Nepal have contributed vital information about the realities on the ground. These insights provide great understanding of the current situation of CWD in Nepal and how policy and practice have taken up the issues.

5.1 The Impact of the Social Model of Disability

One similarity between all analyzed documents is the conceptualization of disability within the social model. By implication, the social model of disability has been powerful in offering new perspectives to tackle the issues faced by disabled children. The model represents the re-imagination of disability as caused by social determinants, rather than the individual's impairment. This concept draws a strong distinction between the words "*impairment*" and "*disability*". While the WHO action plan refers to this important distinction in their disability definition stating that disability is a broader concept comprising "*impairments, activity limitations and participation restrictions*" (WHO, 2014, p. 3), the Nepalese national plan does not mention the term "*impairment*" at all. So, the Nepalese government does not refer to the biomedical model of disability, whereas the WHO keeps elements from it. Adopting the international recognized social model of disability seems to have had positive effects on disabled children in Nepal. All of the interview respondents stressed the progress made both at the national and local level to improve the lives of CWD. For example, the advancement of the disability concept has been perceived as one that especially helped disabled people and their organizations to enforce greater empowerment for CWD (MacLachlan & Swartz, 2009).

The social model leads to greater divergence in defining disability due to the context-specific, socio-cultural factors influencing how disability is conceptualized (Lord & Stein,

2008). Patterns, causes and consequences of disability for children may differ distinctively between countries, but also within countries. For instance, the disparity between rural and urban areas in Nepal as outlined by interview participants is important to realize to be able to effectively tackle disability within Nepal. However, all analyzed documents tend to simplify the concept of disability. By way of example, neither the WHO action plan, nor the Nepalese national policy prominently address CWD. This silencing results in limited attention towards the disabled children's specific needs, as they require different services compared to adult PWD. A discursive effect can be identified in the limited role that disabled children have in the discourse on established actions. Lindsay & McPherson (2011) argue that *"there is a critical need to explore children's suggestions for improving inclusion so they can participate as full citizens"* (p. 810). Watson (2012) supports this statement by claiming that research on disabled children previously did not take notice of perspectives the children themselves had to communicate. Furthermore, Watson (2012) cites Thomas (1999) who states that *"impairments are not (...) irrelevant and they and their effects combine with disablement and any research on disability must engage fully with both"* (p. 196). Hence, the complexity of disability and the individual experiences of it are important aspects to consider. Even assumed homogeneity among disabled children results in methods that may not be appropriate for some CWD, because children with the same condition could have distinct needs requiring completely different support. On the one hand, simplification seems to be required to create feasible solutions. On the other hand, recognition of the complexity of disability is necessary to reach each affected child accordingly.

Nonetheless, Siska and Habib (2013) critique the social model for tending to ignore the impairment of a child, so that the perception on how an ideal situation for disabled children should be is biased towards societal aspects rather than individual requirements. The personal issues a child may have with the impairment are silenced and consequently remain (Shakespeare & Watson, 2002). Therefore, the combination of addressing both the social determinants of disability and the particular circumstances of disabled children can stimulate further progress in tackling barriers and inequalities faced by CWD (Emerson, et al., 2011). To embrace these two aspects, interview respondents suggested to include PWD in decision making processes, so that their perspectives can be taken into account. The Inspire2Care program pursues therefore interventions with the involvement of disabled children, their families and the communities they live in to establish programs that capture multiple factors that result in the disability of impaired children.

5.2 The Vision of Societal Inclusion

As part of the social approach to disability, societal inclusion has become an increasingly recognized concept. Inclusiveness of society for disabled children within current international and national disability policy and practice in Nepal has been conceptualized closely intertwined within the conceptualization of disability. The commitment to strive for inclusiveness of society has been taken up throughout analyzed disability policy and practice. The Inspire2Care project uses a bottom-up approach to create inclusive change for disabled children and their communities and the Nepalese national plan emphasizes likewise social empowerment and mainstreaming development. The WHO action plan refers to supportive and inclusive community activities that shall strengthen mainstreaming in all areas of life. The conceptualization of societal inclusion appears as part of the broader concept of disability to be framed in the same manner in all analyzed documents. These descriptions of societal inclusion are further aligned with similar definitions as can be found in the CRPD and CBR framework (Cobigo, et al., 2012).

Although interview participants observed positive change towards societal inclusion in Nepal, they proposed increased involvement of all stakeholders to foster inclusiveness of society. On the local level, this interlink relates to how the interpersonal interaction between the child and the people in their environment, including family, friends and other community members, shape the disability. Local structures influence the child's well-being by either limiting or extending access to services such as healthcare, school or leisure time activities. At the highest level, political leaders impact structural conditions comprising existing policies and awareness programs for CWD. Therefore, the stakeholder's attitudes, perspectives and values need to be considered in how the life for CWD can be changed for the better. This means that the issue of disability must be recognized by all stakeholders to successfully tackle barriers in the long-run. Siddiqui (2014) argues that "*inclusion is not a series of methods, but a sustained partnership*" (p. 15), referring to the continuous collaboration between all those involved.

The used conceptualizations of disability within the analyzed policy and practice examples imply the non-existence of societal inclusion, so that social inclusion is constituted to be a means to end disability. Hereby, it is important to realize that societal inclusion tends to represent an ideology rather than actual practice. The inclusiveness of society is expressed as an ultimate goal for both policy and practice. For example, the Nepalese national plan intends "*to establish an inclusive (...) society for people with disability*" (Nepalese Government, 2006, p. 6). Cobigo et al. (2012) warn against this use of societal inclusion because the visionary standpoint on inclusiveness can result in misleading, harmful approaches. Societal inclusion is often defined by referring to its binary component, namely

social exclusion expressed by phrases such as the lack of access, opportunity or participation. Hansen (2012) declares that *“we have to accept that exclusion is the otherness of inclusion which means that inclusion presupposes exclusion. If we didn’t exclude we didn’t need to include. At the same time, we need to exclude in order to include. Inclusion and exclusion are two connected and interdependent processes”* (p. 94). However, Simmons et al. (2008) illustrate how important it is to challenge these binaries, including inclusion versus exclusion or able versus disabled. They state that thereby new opportunities are created to explore the complexity of disability. Depending on socio-cultural context, the issues of disability can differ widely between countries and even within countries. By way of example, interview respondents supported this statement by describing different attitudes and structural facilities between rural and urban areas in Nepal. In one community disabled children may encounter problems due to lack of disabled friendly infrastructure, whereas in another community the impact of shame and misperception towards disability is of greater relevance (Goodley, et al., 2012). Consequently, as delineated in the theoretical background section, the holistic approach to address visibility, consideration, access, rights and health by changing the notion of societal inclusion, as resembling an ideal towards everyday practice, may lead to the desired level of quality life for disabled children.

5.3 The Interplay between Local and Global Disability Movements

Another prominent aspect in the analysis is the interplay between global processes and the local situation. The impact of the human rights framework on the international level is evident in the application of human-rights based approaches in domestic policy and practice in Nepal. Not only NGOs have adopted the human rights-based way of expression, but government agencies, too. The integration of this terminology has been argued to be a powerful tool in advocating for people who face disability (Albert & Harrison, 2008). However, as pointed out by Rouger (2009), recognizing disability as a human rights issue does not ultimately result in significant improvement. Loeb (2009) states that only political will and determination as well as a well-functioning social structure can ensure the impact of human-rights based legislation. These issues have been pointed out by interviewees who stated that political commitment is lacking in Nepal, which hesitates to take effective measures against the issues faced by disabled children. Nevertheless, Albert and Harrison (2008) hold that changing the language is the first step towards actual change. De Silva de Alwis (2009) suggests integrating the rights-based approach to disability into broader policy agendas to further mainstream and normalize disability. This opinion is supported by Kieling et al. (2011) who claim that the effective implementation of a rights-based approach can only be achieved by an intersectoral collaboration. An interesting strategy

was framing of disability within the development paradigm. All analyzed document share the recognition of including disability into the overall development strategy within policy and practice. Drew et al. (2011) and Sabatello (2013) argue that this integration may be the only permanent solution to disability. Effectively decreasing vulnerability among disabled children requires changes in structural conditions (Von Braun & Gatzweiler, 2014). Bakker & van Brakel (2012) further affirm that the development paradigm helps to tackle disability by sustainable strategies. To expand capabilities and ensure entitlements to those capabilities are central to sustainable development and thus, the structural change to the situation of disabled children can bring beneficial solutions. Overall, the incorporation of internationally accepted frameworks into national disability policy and practice seems to offer powerful instruments to effectuate inclusiveness of society.

5.4 The Construing Error in Disability Policy and Practice in Nepal

While policy and practice share ideas based on the social, rights-based approach to disability, they find ways to differently communicate this concept in their problem representations. Comparing the response from experts in the field with the existing policies, an essential gap between what policies and practices emphasize can be observed. While the practice example and the expert opinions stress the importance of attitude change and local capacity building, international and national policy maintain service provision and barrier removal as their focus. Respondents describe this discrepancy as an interest clash between governmental agencies and NGOs resulting in limited state funding for disability projects. International and national policy makers may be motivated to promote service delivery due to practicality reasons. The provision of services seems to be more feasible than achieving structural changes. However, to address inclusiveness in society for CWD requires sustainable, long-term approaches to stop that disabled children continue to be disproportionately disadvantaged. According to the interviewees, current efforts to improve the situation for disabled children have been significant, but continuous commitment is necessary to achieve the highest attainable quality of life for everyone in the society. One should keep in mind that societies may not only hinder CWD by creating barriers, but also by not providing facilitators (Borg, Bergman, & Östergen, 2013). Therefore, the attitude change becomes central to change the conceptualization of disability from within. As highlighted by experts working in Nepal and also by the Inspire2Care program of the Karuna Foundation, the mindset of Nepalese people is crucial to address disability. In Nepal the culturally constructed social dimensions play an important role in the identification of how disability is perceived and understood. Nepal's socio-cultural context is characterized by strong collectivist culture highly influenced by religion and superstitious believes (Karr, 2011). Hence, it may be helpful to rethink existing

conceptualizations in order to identify new approaches to persistent issues. The disability discourse exemplifies what implications the further development of concepts can have.

While the shift from the medical model to the social approach has transformed definitional attempts to grasp the multidimensional situation faced by disabled children, disability remains a vague and indefinite concept. To date, accurate surveillance mechanisms are not in place to monitor the incidence and prevalence of disability in Nepal. The varying numbers revealed by the few studies conducted in Nepal skew the picture of the significance of the problem. This lack of evidence-based action has important implications for policy and practice, such as potential misinterpretations of the actual situation and needs of disabled children. Since interview participants confirmed that governmental and organizational practices are generally not done in collaboration, it is of necessity to harmonize methodological procedures and to find mutual consensus on how disability should be defined. Furthermore, the effects of using the term "*disability*" should be reconsidered in future programs, because, as it has been illustrated in the analysis, the concept of disability implies exclusion, and thus disabled children may perceive themselves as something abnormal. This can have important implications for disabled children, such as influencing their self-perception and self-confidence. Hence, reconceptualization of disability by using different terminology may help to empower disabled children and facilitate their inclusion in society.

5.5 Limitations of this Study

When considering the presented results' implications, limitations in the used methodology have to be taken into account. Because of the designated scope and time limitation, the study was limited to the analysis of two latest policies and one practice example. However, as the theoretical framework suggests, the broader historical process is of relevance to evaluate comprehensively problem representation. Therefore, this study may lack essential insights into past development in disability policy and practice attempts in Nepal. Another shortcoming is that the study does not include information on disability or societal inclusion in the official language of Nepal, even though governmental documents are often only available in Nepali. As a consequence thereof, the explored elaborations may be skewed because relevant documents may not have been identified by the chosen search strategy. Given the context-specific comprehensions of inclusiveness of society for disabled children, the different values, perspectives and positions, referring not only to the researcher, but also to those represented within the used literature, may introduce informational bias. Hence, it is acknowledged that provided interpretations can be hardly detached from the different underlying presuppositions.

6 Conclusion

This study has shown that the discourse on disability in Nepal is complex. The unique and distinctive aspects of context-specific realities have shaped the evolving conceptualizations of disability in Nepal. Two important commonalities appear to have decisively influenced contemporary conceptualization of disability, namely the social approach to disability and the rights-based approach to disability. Positive changes have been realized through these recognitions that responsibility lies not only with the individual, but also with the environment in which they live. Nonetheless, the potential for impairments to create barriers independent from surroundings must be heeded. Consequently, the personal experience of each child with an impairment should not be ignored when addressing disability issues in Nepal. Overall, the interplay of policy, research and practice needs to engage fully so as to improve the life of CWD in Nepal. The inclusiveness of society has been proven to be an important concept for approaching disability. To become an effective measure, the transition from theoretical ideal to everyday practice must be made.

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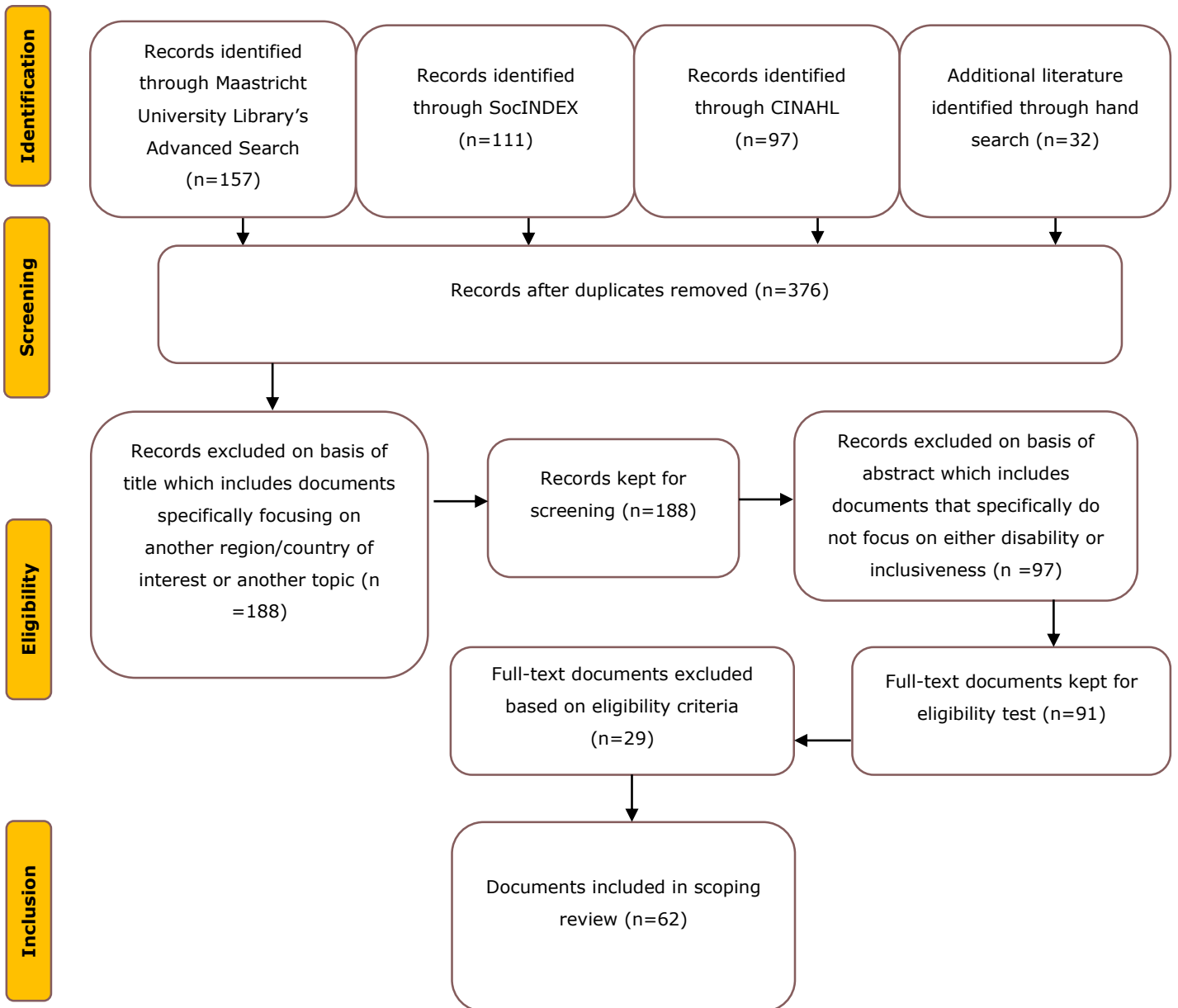
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Appendix 1: Detailed Search Strategy for the Scoping Review

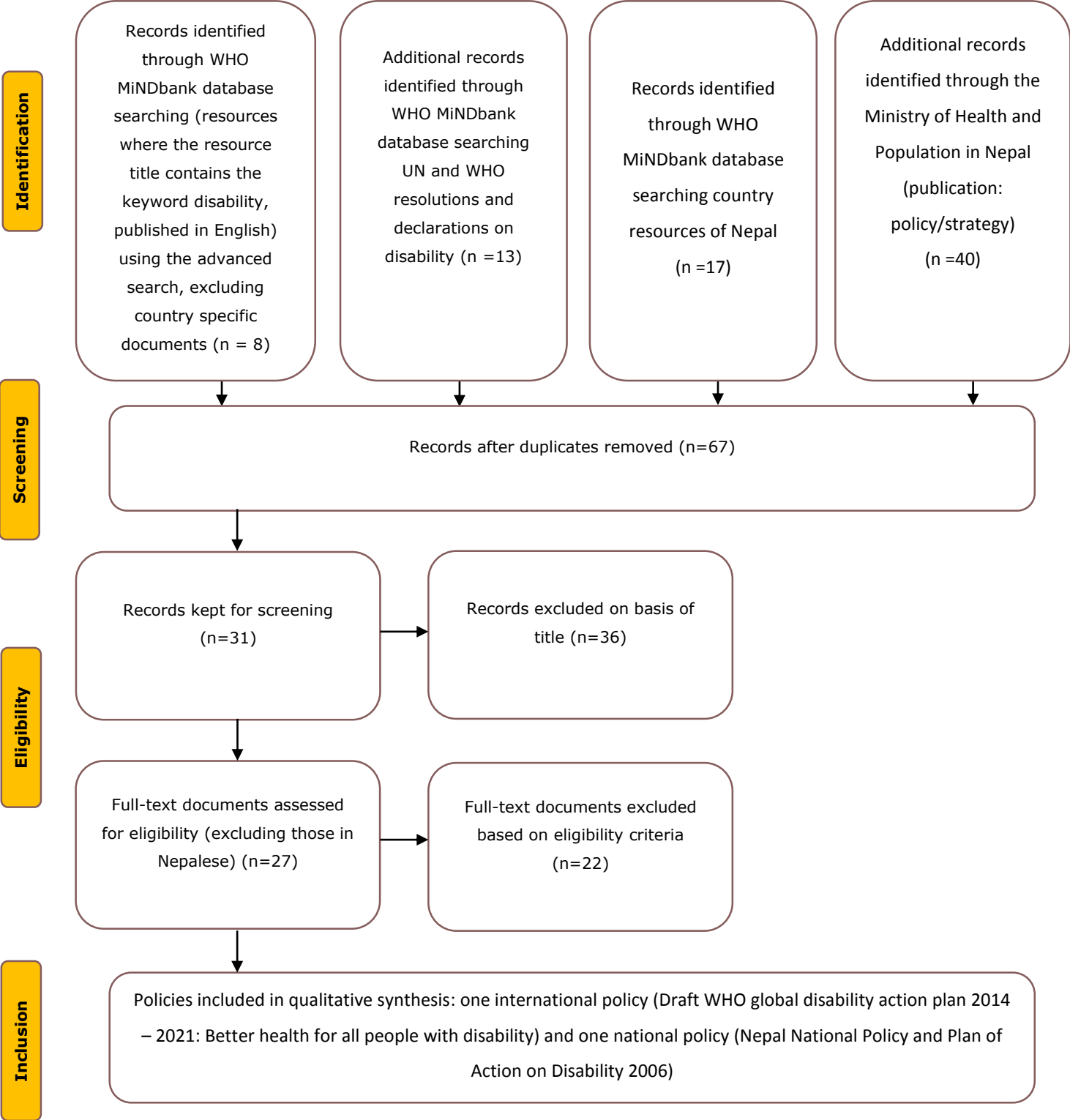
Elaborations are based on the Cochrane 'checklist for developing a search strategy' (Naumann, 2007).

<i>Leading Question: What is the impact of international, national and local practices on the inclusiveness of society for children with disability in Nepal?</i>			
1. Define text words			
International, national and local practices	Inclusiveness of society	Children with disability in Nepal	
PRACTICES	INCLUSIVENESS	DISABILITY	NEPAL
1. Determine synonyms for the text words			
2.1 MeSH			
	"social distance" → <ul style="list-style-type: none"> • Distance, Social • Distances, Social • Social Rejection • Rejection, Social • Social Rejections • Social Acceptance • Acceptance, Social 	"disabled children" → <ul style="list-style-type: none"> • Children with Disabilities • Children with Disability • Disability, Children with • Children, Disabled • Handicapped Children • Children, Handicapped • Child, Disabled • Disabled Child 	"Nepal"
2.2 Thesaurus synonym search			
Practice – "method", "proceeding", "process", "rule" project – "activity", "plan", "program", "proposal", "scheme", "strategy"	"inclusion", incorporation", "involvement" ↔ "exclusion"	Disability - "ailment", "defect", "impairment", "infirmity", "handicap", "barrier", "burden", "impediment", "obstacle", "shortcoming" Child – "adolescent", "baby", "infant", "juvenile", "kid", "minor", "offspring", "teenager", "toddler", "youngster", "youth"	
2.3 Brainstorming for Keywords			
NEPAL Keyword 1: "Nepal" CHILDREN WITH DISABILITY Keyword 2: "disab*" OR "impairment" OR "handicap" Keyword 3: "child*" OR "adolescent" OR "youth" INCLUSIVENESS OF SOCIETY			

Keyword 4: "inclusion" OR "inclusive" OR "exclusion" OR "mainstream"	
2. Search with advanced search at Maastricht University library portal	
(TitleCombined:(Nepal)) AND (disab* OR impairment OR handicap) AND (child* OR adolescent OR youth) AND (inclusion OR inclusive OR exclusion OR mainstream) + language (English) + publication date range 1/1/08 – 6/11/15 + items with full text online	67
(Nepal) AND (TitleCombined:(disab* OR impairment OR handicap)) AND (child* OR adolescent OR youth) AND (inclusion OR inclusive OR exclusion OR mainstream) + language (English) + publication date range 1/1/08 – 6/15/15 + items with full text online	59
(Nepal) AND (Abstract:(disab* OR impairment OR handicap)) AND (TitleCombined:(child* OR adolescent OR youth)) AND (inclusion OR inclusive OR exclusion OR mainstream)	33
(Nepal) AND (disab* OR impairment OR handicap) AND (child* OR adolescent OR youth) AND (TitleCombined:(inclusion OR inclusive OR exclusion OR mainstream))	35
	194
➔ Duplicates removed from these search steps	157
3. Search with SocINDEX	
TX nepal AND TX (disab* or impairment or handicap) AND TX (child* or adolescent or youth) AND TX (inclusion or inclusive or exclusion or mainstream) + 2008 - 2015	2
Nepal AND (disab* or impairment or handicap) + 2008 – 2015	12
Nepal AND (child* or adolescent or youth) + 2008 – 2015	87
Nepal AND (inclusion or inclusive or exclusion or mainstream) + 2008 - 2015	27
	148
➔ Duplicates removed from these search steps	111
4. Search with CINAHL	
nepal AND (disability OR disabled OR impairment OR handicap) AND (child OR children OR adolescent OR youth) AND (inclusion OR inclusive OR exclusion OR mainstream) + 2008 - 2015	1
Nepal AND (disab* or impairment or handicap) + 2008 - 2015	20
Nepal AND (child* or adolescent or youth) + 2008 - 2015	148*
Nepal AND Abstract (child* adolescent or youth) + 2008 - 2015	74
Nepal AND (inclusion or inclusive or exclusion or mainstream) + 2008 - 2015	14
	109
➔ Duplicates removed from these search steps	97



Appendix 2: Flow Diagram of the Search Strategy for the Policy Documents



Appendix 3: The Interview Guide

General Information

Analysis Code:

Interview Date:

Interview Type (Skype/Phone/Mail):

Male/Female:

Background of the Interviewee:

Introduction

I am a master student from Maastricht University in the Netherlands. In course of my Master Thesis in cooperation with the Karuna Foundation in Nepal, I would like to conduct an interview on policy and practice that relate to the inclusiveness of society for children with disability in Nepal. This information will be used to produce an informative paper for my Master Thesis. Your information will be handled with confidentiality.

General Questions

1. What is your background/profession?
2. What projects are you involved in?
3. What is your role in those projects?
4. What type of children do you have contact with?
5. What barriers do these children encounter?
6. What challenges do you face in your daily work?

Specific Questions

1. How would you describe ideal living conditions in a community for children with disability?
2. Who plays a role in creating ideal living conditions for children with disabilities?
3. How would you compare the situation of children without a disability with the one of disabled children in Nepal?

4. What is your perspective on the ability of children with disability being able to participate in the community in Nepal?
5. Have you seen any change in the visibility of children with disabilities in recent years? If so, in what way has it changed; do you see them participate more or less in the community?
6. How do you perceive the accessibility of schools or health care services for children with disability?
7. What barriers have been removed during the recent years and by whom?
8. What barriers may children with disability still face in accessing services (such as school or health care)?
9. What is still needed to improve the situation for children with disability? And who is responsible for this?
10. Do you know any policy that improves the social inclusion for children with disability in Nepal? If yes, what are the strength of these policies? And what are the weaknesses of these policies?
11. How have been these policies implemented on the ground? What have been the successes in the implementation and what are remaining challenges?
12. Do you have any other comment or concern you would like to tell?