

Parenting a disabled child in South Korea: Rewriting disability, parenthood and citizenship

Bogcheon Choi

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ABSTRACT

This thesis is about parental experiences and practices in association with disabled children in South Korea. It is first and foremost about disablement. It aims to expose the inequality and exclusion experienced by disabled children and their families. It was intended to challenge the long-established tradition in Korea of regarding the problem of disability as a personal and family issue, and aims to purposes to enhance the social recognition of the rights of disabled children and their families.

This thesis is also about the development of disability-parenthood. It explores the ways in which parents construct and reconstruct their notions of parenthood and disability through their continual experiences of parenting a disabled child. It intends to resituate parents as potentially active social agents who create their own knowledge about disability. It examines how parents are struggling against disabling forces and acting on behalf of their disabled children in their own lives.

Another main purpose of this thesis is to explore how parents develop their politics of disability by working together. In order to research parents' group activities, this study engaged the participation of parents involved self-help or advocacy groups. The research employed both in-depth interviews and long-term participant observation.

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LIST OF ABBREVIATIONS

ADPER	Alliance for Disabled People's Educational Rights
APCCP	Association of Parents of Children with Cerebral Palsy
APCD	Association of Parents of Children with Down's syndrome
APDCS	Association of Parents of Disabled Children in Seongnam-city
APERDP	Association of Parents for the Educational Rights of Disabled People
CAPDC	Changwon-city Association of Parents of Disabled Children
CTH	Caring Together Home
KAPDC	Kimhae-city Association of Parents of Disabled Children
KPAMS	Koyang-city Parental Association for Mainstream Schooling
SAPDC	Soowon-city Association of Parents of Disabled Children
SAPHRDP	Seoul Association of Parents for the Human Rights of Disabled People
SEPA	Special Education Promotion Act
SWC	Social Welfare Centre
TAPDC	Taegu-city Association of Parents of Disabled Children

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CHAPTER ONE

INTRODUCTION

INTRODUCTION

This chapter provides an overview of the research, beginning with its significance and purposes. I then discuss the key theoretical perspectives that give insights into understanding the experiences and practices of parents of disabled children. It also gives a brief description of the research sample, process and methods employed and finally provides an outline of the thesis contents.

RESEARCH PURPOSE

Where are we? We are the beings that exist but should not exist in this society. Nobody knows our lives. Nobody even listens to our problems. Why don't our children have the right to receive even very basic help and respect from society? You know what the parents of disabled children desire? It is that parents will live one day more than their children. No one realizes what a painful dream this is! Until then, we can do nothing other than fight on behalf of our children.

[Comments from a discussion (summer, 2002) with an activist working in the *Korean National Organization of Parents with Disabled Children* who has a fifteen year old son with Down's syndrome]

The lives of parents of disabled children are almost always complicated and full of exhausting battles; they are frequently thrown into hostile, oppressive environments with too little emotional and material support for bringing up their child. The oppressive environment they face in their everyday lives ranges from exclusion from appropriate education, health and welfare services through to experiences of actual and symbolic violence from others (RIDRIK 2001). However, given the dominant social perception that considers disability as an inherently personal or family problem, these issues have seldom entered the sphere of public discussion until now in Korea, nor have the experiences of disabled people and their families been considered as important social issues even in the academic field (Hong 1997; Jeong 2001).

In order to challenge such disabling conditions, and to make their voices heard in public, the parents of disabled children began to organise various forms of locally-based and national self-advocacy organisations in the late 1990s (Y. Kim 1997). This research was primarily initiated to rectify the problem of the under-recognition of disability problems in Korea. Having witnessed the emergence of parents' groups, my interest extended to their group activities. I wanted to know how their experiences of disablement influenced their engagement in group activities and in what ways they developed disability politics by working together.

In addition to this aspect of the Korean situation, this study also aims to challenge the dominant research approaches to parents/parenting and disabled children. Under the influence of the medical model of disability, research on families with a disabled child has tended to adopt a pathological approach, assuming that a child's physiological impairment 'inevitably' causes a breakdown of the so called

'normal' family life (Ferguson 2001; Read 2000). By adopting a critical disability studies perspective, this research will challenge such underlying assumptions by revealing the ways in which disabling social forces are actualised in the lives of disabled children and their families. Furthermore, against the tendency to represent the parents of disabled children as passive victim-receivers or mere stigma managers, this study will resituate them as potentially active social agents, who create and shape their own knowledge about disability and also challenge the socially claimed notions of disability, parenthood and citizenship without underestimating the oppressive, constraining situations in which they are located.

THE RESEARCH QUESTIONS

This purpose of this research is specified in the questions below:

- How do the parents experience disablement?
- How are the wider social system and culture related to their experiences of parenting a disabled child, and in what ways do these social relations make their children and families different from other families with non-disabled children?
- How do the parents construct and reconstruct their parenthood through their experiences of rearing a disabled child?
- How do the parents transform their perceptions of disability?
- How do the parents develop an awareness of group politics?

- Why do they decide to come together and in what ways do they develop their community?

KEY THEORETICAL PERSPECTIVES

The social model approaches

At a broader level, our approach to disability affects how we understand families with a disabled child. The birth of a disabled child has been traditionally seen as a personal and family tragedy (Shakespeare and Watson 1998), and research on families with disabled children usually takes a therapeutic approach (Turnbull and Turnbull 1986; 1990). It tends to highlight individual faults and deficits by focusing on personal and psychological variables. In so doing, it excludes a consideration of the broader social and cultural forces that make the family disabled (Read 2000).

This study uses a social model perspective as a backdrop to analyse the experiences of families with disabled children. Adopting the critical perspective underpinned by the social model of disability, I hold the view that disability should be understood as a distinctive form of social oppression imposed on impairment. This fundamental view was also applied to the understanding of families with disabled people: there is no inevitable causality between having a disabled child and the disablement of the family; as Dowling and Dolan aptly put it:

Although families with a child with disabilities suffer real inequalities, the concept of these families is nevertheless socially constructed. This is a very

different concept from the old fashioned idea that a child with disabilities disables the whole family and that there are handicapped families rather than just handicapped children. What we are saying is that the child does not handicap the family – society does.

(Dowling and Dolan 2001: 22)

Applying the social model of disability to the family allows the broader range of inequalities facing families with disabled children to be made visible, and challenges the traditional, pathological approaches to families with a disabled child.

Life course approach

A life course approach provides several vantage points for exploring the experiences and practices of parents of disabled children. First of all, exploring the life stories of disablement provides a rich understanding of how disability is actualised in the real world (Priestley 2003) and how the life opportunities of both disabled children and their parents are differentiated from others by social and cultural forces.

A life course approach also helps us to make sense of the development of disability-parenthood over time. A number of studies have shown how parents develop their parental career and redefine their roles and responsibilities through their continuous experience of disability. For example, Traustadottir (1991, 2000) found that the mothers of disabled children extended their parental practices from caring for their own child to embracing more public work, such as advocacy. Some writers suggest that the parents' experiences of living with a disabled child cannot be fully understood when investigators examine only the short-term responses (e.g. Curry 1995; Larson 1998; Scorgie and Sobsey 2000). In a similar way, some authors

have emphasised that parents experience a range of transformational outcomes associated with parenting over time, including changes in their perceptions of disability in general and their own children in particular (Landsman 1998, 1999; Landsman and Riper 2007; Read 2000). Thus, the formation of disability-parenthood can be understood as a lifelong process rather than a primary given.

Thinking of parenting as a social-cultural field

Not only do researchers tend to ignore the socio-cultural context within which the parents of disabled children live, they also often overlook how parents are struggling against, and are agentic within, these contexts. In relation to my study, it can be argued that parental practices are constrained and governed by disabling social environments and, on the other hand, that the social arrangements and discourses of disability are challenged and reformulated by parents (Rapp and Ginsburg 2001). This viewpoint helps us to capture the contested nature of the parental embodiment of disability: the parents of disabled children, on the one hand, have been among the most active advocates of disability rights and the need to build disability communities (Hillyer 1993; Rapp 2000) and, on the other, have often been a conduit for reproducing disabling social forces; for example, through fostering children's internalisation of oppression (Morris 1993; Shakespeare 2002).

In order to appreciate the contested nature of parental practices and the embodiment of disability from a critical disability perspective, I suggest considering parenting a disabled child as a 'social-cultural field'. Borrowing Bourdieu's idea of fields (Bourdieu and Wacquant 1992), parenting a disabled child can be considered a

structured, unequal, and socially constructed (disabling) environment, within which the parents are embedded and to which they constantly respond. In Bourdieu's use of the term, 'fields' are understood both as configurations of social forces and as sites of the struggle to maintain or transform those forces (ibid., p. 101). Thus, his notion of fields is distinct from views that stress total domination; for example, 'total institution' (Goffman) or 'orders of discipline' (Foucault) (Swartz 1997: 117-29). For him, fields are 'sites of resistance as well as domination, one being relationally linked to the other' (ibid., p. 121). For the purpose of my study, this dual nature of a field makes it particularly relevant for the analysis of parental experiences and practices. Thinking of parenting a disabled child as a social-cultural field aims to capture the dialectics of power and powerlessness in the structuring of parenting a disabled child. It also aims to highlight the significance of the parents' struggles and resistance without underestimating the domination of social (disabling) forces and relations.

CONDUCTING THE RESEARCH

Methodological considerations

In order to explore the parents' experiences and perceptions in depth, a qualitative research methodology was adopted, which involves exploring the world of the parents in order to describe and understand the social environment from their point of view. Qualitative studies are recognised as making a distinctive contribution to the

studies of parents of disabled children because they enable the parents' voices to be heard more directly. There has been an increasing interest in the parents' own accounts of their lives, alongside the growing parents' movement, which claims the right to interpret their experiences and reality in their own terms (Hillyer 1993; Murray and Penman 1996).

It was also decided that the research should contain a participatory element in terms of the knowledge production. There is a growing amount of literature on the participatory paradigm in relation to disabled people (Oliver 1992; Zarb 1992). This approach is based on a number of ideas. Firstly, the conventional research relationships, where the researched are the objects of the investigation, fail to recognise the extent to which expertise resides in the research participant. Secondly, the relevance of the research needs to be considered in relation to the commitment to challenging the disabling society. This philosophical underpinning was applied to the research on parents with disabled children. In the process of the research, in various ways, I tried to allow the participants to express their expectations and wishes regarding the research production – what kind of knowledge production would they consider beneficial? This was necessary because I wished to ensure that the issues that I wanted to highlight would coincide with the participants' wishes. The parents' comments on knowledge production were categorised under three points: it was important (a) not to represent their lives with a disabled child as 'tragic', 'pitiful' or 'abnormal'; (b) to make society acknowledge the problems the children and their families face; and (c) to make others recognise and respect their efforts, whether personal or collective, to change their social situation. I regarded these participants' comments as a basic reference for analysing and presenting the research findings.

Research process, sample and methods

The fieldwork spanned a period of twelve months, beginning in September 2003 and continuing until August 2004. In order to add depth to understanding the parents' experiences of disablement and group activities, multiple research methods were employed. The in-depth, semi-structured interview method was employed as one of the main research instruments. Twenty-nine parents, who were involved in parents' self-help or advocacy groups, were interviewed. Participant observation was another main research method for collecting the data. I used the APCCP (Association of Parents of Children with Cerebral Palsy) as the primary base for the long-term participant observation and also actively participated in the various forms of other parents' gatherings in order to obtain a rich knowledge of the parental group activities.

THE THESIS OUTLINE

This thesis consists of nine chapters. Chapter 2 reviews the relevant literature and the theoretical perspectives that are employed as a lens for the analysis. It firstly discusses the key theoretical definitions of disability, then proceeds to explore the literature on families with disabled children and disability-parenthood.

Chapter 3 provides a brief overview of disability problems in Korea, then discusses the methodology, research practice, and the process of the data collection and analysis. It starts with considerations of the ontological and epistemological

stance adopted in conducting this research, followed by an explanation of the fieldwork process and associated activities, such as the methods and techniques used for the collection of the relevant data.

Chapter 4 investigates the parents' experiences of transition to disability-parenthood. It explores how their early experiences are influenced by and intersect with the wider social and cultural circumstances. It examines various features of the disabling barriers that they experienced in coming to terms with living with a disabled child. It highlights how their feelings of biographical disruption and experiences of anomie were shaped to a great extent by the unsupportive social conditions.

Chapter 5 presents the parents' accounts of their everyday family lives. It explores how an unsupportive social environment constrains their daily life management, then discusses the issues associated with caring. This chapter also highlights the mediating roles that the parents play in their daily lives in order to enhance their child's acceptance.

Chapter 6 focuses on the parents' experiences and engagement in their child's schooling. It emphasises that the school is the site where the parents witness, experience and struggle with a number of disabling forces. It examines the salient features relating to the exclusion and inequalities experienced by disabled children, and their parents by association, in the school setting.

Chapters 7 and 8 examine the parents' experiences of group working. In Chapter 7, I firstly trace the personal pathways whereby they become engaged in parents' group activities. In doing so, this highlights how their engagement is firmly grounded in their experiences of disablement, which range from the unmet needs of

parenting, isolation and the deprivation of ordinary life opportunities to experiences of direct discrimination. It also emphasises that their participation should be understood as a way of seeking solutions to the problems they face, while at the same time, forming part of the process of transforming their parental practices in more collective ways in order to challenge the disabling forces.

Chapter 8 investigates how the parents develop their politics of disability through collective working in their self-help groups. It firstly examines how the parents develop an empowering relationship and construct their voices in a collective way, examining in particular the activity of sharing their experiences of suffering. It then discusses the salient features of their community building and which cultural values are developed in the process. The core counter discourses constituting parents' disability consciousness are also illustrated.

In Chapter 9, the thesis concludes by returning to the research questions and considering the theoretical and practical implications. The research findings are related to the theoretical discussion of the nature of disablement with respect to the family, parental practices, the development of parenthood, and the parents' politics of disability.

A NOTE ON TERMINOLOGY

The terms 'impairment' and 'disability' will be employed in different senses throughout this thesis. In accordance with the growing tendency in disability studies, 'impairment' refers to 'a medically classified condition', while 'disability' is 'a

generic term used to denote the social disadvantage experienced by people with an impairment and those close to disabled people by association (Barnes et al. 1999: 7). Where the interviewees spoke of their child's physical, cognitive, and intellectual condition using the word 'disability', I translated it differently in accordance with their intended meaning.

CHAPTER TWO

UNDERSTANDING DISABILITY, FAMILY AND PARENTAL PRACTICES

INTRODUCTION

This chapter reviews the literature and research on the experiences of parents of disabled children. The ways of understanding disability, explicitly or implicitly, has guided how the lives of disabled children and those close to them are explained and theorised (Ferguson 2001). Firstly, I discuss what I regard as the key theoretical questions: What is disability? And how can it be explained? I will start by defining and providing a brief overview of the theoretical underpinnings of disability problems. Then, I will examine the theoretical debates on families with disabled children and review the research that documents the problems related to the parenting of disabled children. Finally, I will explore the literary sources that theorise about and document the characteristics of disability-parenthood to provide a framework for investigating the experiences and activities of the parents of disabled children.

THEORETICAL APPROACHES TOWARDS DISABILITY

There has been a paradigm shift in understanding disability that can be succinctly summarised as a transition from the individual to the social model of disability - in UK terms at least. In this section, I will set out the fundamental perspectives for analysing disability issues that guide my research project. These are: (a) a social-relational approach; (b) examining disability as a form of social oppression and as a terrain of resistance; and (c) identifying disabling values as hegemonic ideologies.

The social-relational nature of disability

Disability has been defined in many different ways over the years; unsurprisingly, these definitions have been influenced by various historical, social and ideological practices. For many years, professional research and policy has been dominated by the 'medical model' that equates disability with chronic illness and ascribes a 'sick role' to the individual (Barnes et al. 1999). Disabled people are defined and classified in terms of their physiological dysfunction or limitations. It has been assumed that someone with impairment would inevitably find it difficult to perform 'normal' activities and, as a consequence, would lack the ability to fulfil normal social roles (e.g. Parsons 1951). Thus, disabled people's experience of disadvantage and exclusion in important areas of their social lives, such as employment and education, has been viewed largely as an individual problem caused by impairment. From this perspective, the appropriate response was either to 'cure' the problem of the bodily condition or to help the individual to 'adjust' to their circumstances (Oliver 1990).

Closely related to this perspective is the ‘personal tragedy’ model (Oliver 1983). Having an impairment is equalised with being ‘less than whole person’ and, in order to overcome their predicament, disabled people are expected to make efforts to ‘rehabilitate’ their ‘personal defects’ and achieve less valued social roles (Barnes and Mercer 2003).

Disabled scholars and activists have criticised the shortcomings of the traditional, medical and individualistic approaches and engaged in developing a new, radical reappraisal of disability issues. Undoubtedly, the most significant achievements have arisen from the development of the social-political interpretation, or social model in UK terms, of disability. In order to depart from biological deterministic and essentialist notions of disability, the social model approaches conceptually separate impairment and disability. In this model, disability is redefined as the product of complex social structures and processes. The disablement and restriction in disabled people’s experience is created by the social barriers and unequal relations between disabled people and the rest of society, rather than being simply caused by physiological dysfunction or difference:

The experiences of disabled people are of social restrictions in the world around them, not of being a person with a ‘disabling condition.’ This is not to deny that individuals experience ‘disability’; rather it is to assert that the individual’s experience of ‘disability’ is created in intersections with a physical and social world designed for non-disabled living.

(Swain et al. 1993: 2)

Social model approaches also define disability as the collective social experience of discrimination and exclusion, not simply as the condition of the victims of individual circumstance:

Disability, according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalised throughout society.

(Oliver 1996: 33)

It should be noted that identifying disability as a social construction and shifting the analytical focus from the bodily condition to the social environment does not simply replace 'biological determinism' with 'social reductionism' (that is, all restrictions of disabled people are socially caused), as is argued by some medical sociologists (e.g. Bury 1996). Nor does this undermine the significance of impairment as constituting the embodied experiences of disabled people. To solve the rather confused understanding of impairment and disability, Carol Thomas (1999) proposes a social-relational reframing of the concept of disability. She points out that there have been two contrasting interpretations of disability in circulation. By distinguishing the 'property-notion' of disability from the 'relational-notion', she re-emphasises that there is no essential relationship (or inevitable causality) between having an impairment and being disabled. Even though 'impairment effects' (that is, restrictions of activities caused by illness or impairment) and disability interact and meld together in the lived experiences of disabled people, disability is rooted in an unequal social relationship and engendered only within certain social contexts:

Disability is about restrictions of activity which are socially caused. That is, disability is entirely socially caused. But some restrictions of activity are

caused by illness and impairment. Thus some aspects of illness and impairment are disabling. But disability has nothing to do with impairment.
(Thomas 1999: 39; emphasis original)

However, the conceptual distinction between disability and impairment need not be mapped onto the dualistic notions of social versus biological or cultural versus natural (Thomas 1999: 42-3). In fact, impairment is often created by social conditions (for example, poverty) (Abberley 1996). Impairment effects are shaped through the ‘interaction of biological and social factors’ and are also ‘bound up with socio-cultural naming’ (Thomas 1999: 43). Following her argument, this study accepts that disability cannot be understood in a holistic way without understanding the impairment effects or recognising the social forces and relations in which such impairment effects are articulated as a specific form of disablement.

Disability as a form of social oppression and a site of resistance

Perhaps the strongest challenge to the existing ideas about disability is the argument that disability should be regarded as a form of ‘social oppression’ (Abberley 1987; Barnes 1996; Oliver 1990). As we observe in human history, the operation of oppressive mechanisms in relation to certain social groups has been justified and naturalised through biological essentialism, that is, by attributing unequal social status to biological deficiency or shortcomings. Such biological essentialism, as seen in the history of women and black people, has been strongly rejected using critical notions of the social power and relations in which they are embedded. However, with regard to disabled people, there has been no such reversal in popular thinking or even

in the social scientific accounts of the experiences of disabled people (Barnes and Mercer 2003; Linton 1998).

In contrast, disability activists and theorists have begun to identify certain social forces and relations whereby disabled people are constrained as a distinctive form of social oppression imposed on impaired bodies (Abberley 1987; Barnes 1991; Oliver 1996). Within disability studies, the term 'disablism' has been frequently used to denote a specific form of social domination and oppression that systematically differentiates disabled people from others and excludes them from mainstream social activities (Barnes and Mercer 2003; Thomas 1999). In order to elaborate the social operation of disablism and its oppressive features, I shall employ Iris Marion Young's identification of the main features of social oppression: exploitation, marginalisation, powerlessness, cultural imperialism and violence (1990: 48-63).

The traditional notion of *exploitation* based on a Marxist perspective was explained according to class structure and labour exploitation in the relations of capitalist production. Of course, the notion of labour exploitation of one group by another within the relations of economic production is difficult to apply directly to the current situation of disabled people who are excluded from the labour market (Barnes and Mercer 2003). However, if we move beyond a monolithic notion of work by incorporating unpaid and domestic care labour, the exploitation of care work - notably carried out by women - is another dimension of the exploitation of labour in sustaining social order and power arrangements (Kittay 1999; Sevenhuijsen 1998; Tronto 1993). From a disability perspective, the social assignment of care work to disabled people (and their family members) can be interpreted as the exploitation of labour in the sense that the social nature of interdependency and relevant

responsibility for 'dependency work' is inappropriately distributed (Kittay 1999).

From the viewpoint of disabled people, *marginalisation* is the most significant feature of social oppression (Linton 1998). By operating through various institutional mechanisms, marginalisation perpetuates the 'systematic exclusion' of disabled people from the mainstream of social activities (Barnes 1991). It is important to note that marginalisation is not simply a lack of life chances or opportunities in an individual sense, but entails 'structured patterns' which hinder disabled people from obtaining and accumulating economic, cultural and social capital (Oliver and Barnes 1998). Such marginalisation of disabled people directly results in a realisation of another form of social oppression, *powerlessness*. Disabled people and their communities have little authority and power to control what to do with their lives, notably in their treatment by medical professionals and bureaucratic policy makers (Morris 1993; Priestley 1999). In addition, impairment and disability are used as classifications to divide the 'normal' body from the 'abnormal' body, and so assign disabled people into inferior and deviant groups (Shakespeare 1994, 1996; Thomson 1997). *Cultural imperialism*, which operates through various forms of cultural representation, is a key oppressive mechanism used to objectify and naturalise disabled people as 'other' (Priestley 1999). I will return to this issue in more detail in the next section. *Violence* imposed on disabled people is a commonly reported social phenomenon across societies, ranging from direct physical attacks to symbolic abuse (Barnes and Mercer 2003).

Employing Young's typology of social oppression, I have discussed the multi-dimensional oppressive features of disablism. Following disability theorists' socio-political approaches, I maintain that disablism should be understood as a

distinctive form of 'systematic social domination and oppression' which is actively operating in the social world. It is constituted by social forces and relations, and reproduces the existing social arrangements and power relations alongside the strict binary categorisation of the 'abled' versus the 'disabled'. Three further points should be noted. First of all, disablism is not only operating according to its own distinctive set of dynamics but is also overlapping or intersecting with other forms of oppressive mechanism (e.g. sexism and racism) – that is, it is the realisation of 'multiple' or 'simultaneous oppression' identified by some disability theorists (Begum 1992; Lloyd 1992). Secondly, disablism is dispersed and manifested in various forms and at different levels. For example, as well as being evident in the forms of institutional practices, it expresses its oppressive power in disabled people's process of self-identity formation. Socially constructed negative meanings, ideas and stereotypes about disability sometimes result in 'profoundly exclusionary consequences by working on their sense of personhood and self-esteem' (Thomas 1999: 47-8). Thirdly, it is important to note that disablism does not express its oppressive power simply in a tyrannical way (Fawcett 2000). Borrowing Foucault's (1979) ideas, it can be said that disablism/ablism express their 'productive power' to govern and discipline disabled people through both discursive and non-discursive mechanisms. For example, in rehabilitation practices and relationships with professional experts, disabled people and their families are often governed by disablism, in which disabled bodies are objectified and regulated (Davis 1995; Stiker 1997).

Insofar as the construction of disability is embedded in certain social forces and relations, certain ways of defining and treating disabled people in the social world are not a natural but a 'historical invention' (Davis 1995). Repositioning

disability as a form of social oppression provides, in both theoretical and political senses, the space to challenge the social barriers and exclusion that disabled people encounter from the citizenship rights perspectives. At the same time, it enables us to relocate disabled people (and their communities) as significant social agents who interpret, criticise and reshape the existing social orders and relations (Morris 1991; Oliver and Barnes 1998). In this context, disability is no longer a fixed phenomenon, but, rather, a social terrain to be reconfigured, struggled against and changed.

Disabling values as hegemonic ideology

I have argued that the social practices of disability can be understood as forms of social oppression which are operating in a number of ways. Here I discuss some of the dominant cultural disabling values in modern societies and their ideological effects in forming and sustaining the existing social relations of domination and subordination.

The culture of tragedy

As disability theorists have underlined, the ideas of 'tragedy' seem to be the most common, consistent theme in the cultural representation of disabled people (Barnes 1992b, 1997; Hevey 1993). The ideas of tragedy have been widely employed as a popular metaphor to depict disabled people as useless, helpless or impotent (Shakespeare 1994). Contemporary studies suggest that such imagery persists in the mass media representations. For example, Biklen (1987) argues that the U.S. media portray disabled people and their lives as sorrowful, painful, desperate, and defeated.

In addition, only a limited number of disability issues are portrayed - such as charity events, fund raising and personal accomplishment stories. A similar picture is found in the media representation of disabled people in Korea. Yi (2001), in his analysis of the main newspapers reporting disability issues, notes that the language used is frequently negative and oppressive, tending to marginalise the day-to-day realities of disabled people. He also emphasises that Korean newspapers exclusively focus on stories of the 'special achievements' of disabled people. Their high-ranking scores in national exams and success in holding down a professional job are often portrayed under the title of 'overcoming great odds'. The underlying message is that disabled people generally cannot achieve or undertake such ordinary life goals. Similarly, an annual monitoring report (DPF 2002) shows that Korean TV has two main ways of representing disability issues: focusing either on the exclusively pitiful, stressful, tragic lives of disabled people and their family members, or on the 'heart-rending stories' of non-disabled people which portray their assistance as 'angel-like behaviour'. In relation to my study, the significance of cultural representations of disability as tragedy is twofold. Firstly, its popular negative assumption is frequently reproduced within the professional literature on disabled children and their families. Secondly, it hinders us from apprehending disability problems from a social perspective.

The culture of the imperfect and the abnormal body

The cultural construction of disability has been dominated by representations of the impaired and imperfect body (Hevey 1992; Thomson 1997). With the growing dominance of the medical paradigm, bodies have been measured, classified and

regulated in the name of cure and improvement (Shilling 1993; Turner 1984). Furthermore, as Foucault (1980) asserts, the 'politics of health' rationalised by bio-medical knowledge, imposes a 'normalising gaze' on human bodies, defining new boundaries of the pathological and abnormal. The 'politics of scaling bodies' in relation to the bio-medical norms has been the crucial mechanism that constructs the social and cultural categorisation of acceptance (Davis 1995; Thomson 1997). In this process, impaired bodies have been represented as 'dangerous' and 'deviant' because they are perceived as being out of control (Wendell 1996). Not only are they conceived as a violation of the physical norms but also they are represented as a threat to the ritualised social behaviours and norms (Thomson 1997). Similarly, Hugues (2000: 558) stresses that 'medical distinctions [of bodies] are powerful cultural distinctions which promote and reinforce social hierarchy' and consequently perpetuate the 'aesthetic invalidation' of disabled people (e.g. incapacity and deficit of credibility). Such a medicalisation of bodies has been particularly significant when set alongside the development of the 'late-modern body project' that celebrates healthy, sexy, perfect and normal appearances, and, at the same time, enforces self-reflexive control of and responsibility towards our own bodies (Shilling 1993; Turner 1992). In relation to parents with a disabled child, the cultural construction of disability as bodily abnormality and imperfection is significant because it has been frequently mirrored in the increased social perception of the parental responsibility to have a 'perfect and healthy' child (Landsman 1998, 2005; Press et al. 1994). As a result, having a disabled child is often regarded as evidence of the lack of 'normal' parenthood (Greenspan 1998; Gregory 1991). Furthermore, the cultural principle of 'normality' regarding child development imposes on the parents the moral obligation

of fixing or modifying the child's functional performance. As Hillyer (1993) emphasises, under the dominance of rehabilitation discourse, parents of a disabled child are valued according to the degree to which they help to overcome the child's limitation: the 'good parent' is someone who achieves successful results which approximate to the milestone of 'normalcy'.

Culture of (in)dependence

Reifying disability as a state of 'unavoidable' dependency is one of the most dominant representations in the public culture and policy narratives (Morris 1993; Priestly 1999; Shakespeare 2002). In popular thinking, disabled people are marked as 'essentially' different from the rest of the population, being frequently depicted as embodying an inevitable burden, the loss of adulthood (childlike), a lack of competence and autonomy, and the incapacity to manage one's life (Jenkins 1998; Priestly 2003). In this context, disabled people are always conceived as inferior, helpless, and, at best, 'secondary citizens' in modern societies. Within disability studies, it has been argued that assigning disabled people to a distinctive dependent group is a reflection of the dominant cultural perception of independence constructed within industrial societies; in particular, the idea of being able to do things without the assistance of others, to be self-sufficient and self-reliant (Morris 1991; Shakespeare 2002).

In common sense usage, dependency implies the inability to do things for oneself and consequently the reliance upon others to carry out some or all of the tasks of everyday life. Conversely, independence suggests that the individual needs no assistance whatever from anyone else and this fits nicely with the current political rhetoric which stresses competitive individualism. In reality, of course, no one in a modern industrial society is completely

independent: we live in a state of mutual interdependence. The dependence of disabled people therefore, is not a feature which marks them out as different in kind from the rest of the population but different in degree.

(Oliver 1989: 8)

In their research, Fraser and Gordon (1997: 125) stress that the devaluation of dependence and binary notion of dependency and independency are the creation of modern thought rather than a universal truth. They argue that, in pre-industrial societies, 'dependency was a normal, as opposed to a deviant condition [and was] a social relation, as opposed to an individual trait'. Some feminist theorists of care ethics also have pointed out that the atomistic perception of independence as the ideal self - dominated by 'work ethics' - has not only obscured the fact that dependence on others is an ontological precondition of human existence, but has also objectified people needing the help of other (and also care-takers) as second-class citizens (Kittay 1999; Sevenhuijsen 1998; Tronto 1993; Williams 2001; Young 1995). In a similar way, some disability theorists have emphasised that we need to reformulate individualistic, mechanistic notions of competence and autonomy from a social-relational perspective in order to challenge the prevailing accounts of the dependence of disabled people as abnormal or deficient, in order to valorise the diversity and difference that disabled people embody in contemporary societies (Jenkins 1998; Priestley 2003; Reindal 1999; Shakespeare 2002).

I have discussed so far a set of socio-cultural disabling values that are dominant in contemporary societies. In a sense, it can be said that they have functioned as 'explanatory devices and justification schemes' regarding the disadvantaged social position of disabled people and also as 'symbolic violence' toward disabled people. Throughout this dissertation, by employing Gramsci's

(1971) ideas on culture, I consider such disabling cultural representations and values as a form of hegemonic ideology (or ideological effects) that naturalises the existing social relations of domination and subordination.

RESEARCH TRENDS AND KEY THEMES IN STUDIES ON THE DISABLED FAMILY

In this section, I turn to a consideration of the key themes in the debates on studies of parents with disabled children that had been conducted in the last few decades. My specific concern lies in building some basic standpoints for conducting my study by dialoguing with the key thematic issues in the literature.

Beyond a pathological approach

Ferguson (2001), in reviewing the literature conducted after World War II, argues that the research on parents with disabled children can be characterised as a direct application of the medical model of disability. As already discussed, the view that having impairment is a determinant factor creating personal tragedy is a core assumption in the paradigm. In a similar way, most early research on families with a disabled child adopted a pathological approach, taking the view that ‘a handicapped child makes a handicapped family’ (MaCormack 1978, quoted in Read and Clements 2001). Without critical questioning the social construction of disability, most research has tended to treat the disabled child as a ‘pathological property’, assuming

that there is a simple, unavoidable causal relationship between having a disabled child and family pathology, such as family malfunctioning and the lack of 'normal' family relationships (Darling 1979; Ferguson et al. 2000; Middleton 1996; Thomas 1982). This approach has frequently produced biased research in which the impact of a disabled child on the parents' psychological well-being and family life is described in highly negative terms, replete with examples of parents who are quite unable to manage a disabled child (Ferguson and Asch 1989; Read 1991). The underlying message in the literature is that a disabled child is undesirable and to be aborted if at all possible (Ferguson et al. 2000; Thomas 1982). Indeed, where parents have reported the beneficial effects of having a disabled child, these have often been dismissed as evidence of 'denial', emotional 'rejection' or an attempt to alleviate their guilt (Featherstone 1981; Stainton and Besser 1998).

In the 1980s, a number of scholars and parents began to challenge this traditional, pathological approach. Three themes have been most commonly identified. Firstly, the parents' response towards a disabled child is not always negative, nor is the child's impairment the sole factor in the parents' perception of their children (Ferguson 2001; Ferguson and Asch 1989). It has been reported that many parents describe their disabled child, like their other children, in terms of love, pride, rewards, and stresses, and emphasised their children's individuality, personality and achievements (Beresford 1994; Glendinning 1983; Goodey 1991). For example, Beresford (1994: 59) observes that 'parents do not view their child as a disability. They describe their child as an individual who has limitations and difficulties arising from the disabling condition'. It has also been noted that parents' emphasis of the positive aspects of their children should not be interpreted simply as

a 'denial of disability' or an 'irrational' or 'romanticised' response (Hillyer 1993; Read 2000; Reinders 2000). Many parents regard it as essential in carving out 'defensive spaces in their lives that foster and enhanc[ing] the well-being of all family members' against oppressive social environments (Read and Clements 2001: 16).

Secondly, the impact of a disabled child on family life should not be interpreted in pathological terms, even though the difficulties that parents experience in rearing disabled children are different from those experienced by parents of non-disabled children. It has been acknowledged that, without neglecting the social pressure that they are under, many parents experience numerous benefits and positive outcomes though parenting their disabled children; for example, family harmony (cohesiveness), spiritual growth and a deep understanding of the lives of others (Bower and Hayes 1998; Ferguson et al. 2000; Reinders 2000). Rather than characterise the relationship with their disabled children as a burden to be shouldered, many parents tend to describe their relationships as 'mutual', 'reciprocal', or 'inter-subjective' (Ferguson and Asch 1989; Gray 1997; Hillyer 1993; Landsman 1999).

Thirdly, in general, the professional literature on the disabled family has been shaped by the legacy of psychoanalysis, tending to focus primarily upon the attitudinal and/or behavioural adjustment or maladjustment of the parents and other family members, while the significant needs and circumstances in their lives are neglected or, at best, treated as secondary issues. As a result, policy derived from the traditional research is concerned with 'fixing' the personal and family qualities which are identified as the barrier to adjustment, rather than with a 'context-changing' approach to the social environment (Trickett et al. 1994: 18). The therapeutic

intervention that psychological and other traditional disciplinary works offer may help parents to cope with certain emotional problems. However, it has been argued that limiting our understanding of the experiences of disabled families to 'intrapsychic and intrafamily issues' has perpetuated the conventional idea that disability is a problem to be solved through individual or family intervention (Philip and Duckworth 1982; Read 2000). More problematically, much of the psychological literature has contributed to pathologising the parents by attributing the problem of the child and family to the parents' deficiency or failure. This dominant research paradigm has been challenged in recent years through the development of disability studies. A growing number of studies has suggested a reappraisal of what had been identified previously as 'pathological' features by addressing environmental contingences. A shift from a child-/family-specific focus to environmental contexts had led to the disabled family being understood in terms of the broader social, cultural and political contexts, as well as in relation to the support systems (Turnbull and Turnbull 1986; 1990).

The disabling conditions of good parenting

There are contested ways of representing the problems that parents encounter in rearing a disabled child: firstly, through a representation of the child's impaired body, and, secondly, through the representation of the disabling barriers that impact on parenting. Without neglecting the parents' particular experiences and their constitutive nature of parenting, a number of disability theorists have argued that we need to move the analytical focus from a child's impairment or his/her parents'

characteristics to the social conditions which disable them (Dowling and Dolan 2001; Middleton 1996; Priestley 1998; Shakespeare and Watson 1998). Here, I examine some of the central themes that emerge from the research on the disabled family, and discuss them in terms of the disabling condition of parenting a child with an impairment, and the disablement that the parents experience as a group.

Material, financial and practical problems

It has long been established that the presence of a disabled child makes a significant financial impact upon a household. As widely noted, this results from two main factors: the cost of meeting the special needs of the child are high and therefore the expenditure increases (e.g. on special equipment and continual medical treatment); at the same time, the child's needs for extra care reduce the opportunity of the parents, especially the mothers, to participate in the labour market (Baldwin 1985; Baldwin and Carlisle 1994; Glendinning 1983; Twigg and Atkin 1994). While welfare benefits compensate for the care labour and disability-related costs in some countries, many studies have demonstrated that there is a substantial discrepancy between the benefit entitlement and the minimum essential costs associated with disabled children's needs (e.g., Dobson and Middleton 1998). Unsurprisingly, in societies, including Korea, that lack a developed welfare policy and welfare benefits entitlement (e.g. disability allowance), the presence of a disabled child can engender extreme material hardship (Byeong et al. 2003; KWSS 2002).

As a result of these factors, the living standards in households with a disabled child are lower than those of comparable families in the general population (Read and Clements 2001), and it should be recognised that a family with a disabled

child is at a great risk of poverty (Ball 1998; Daly and Leonard 2002). Some recent research has drawn attention to the particularly vulnerable groups among families with disabled children; for example, families with more than one disabled child and lone-parent households (Lawton 1998; Tozer 1999). The researchers reported that, in these families, there is an increasing rate of parental unemployment, greater hardship in balancing income and expenditure, and a greater likelihood of being poor.

The restricted financial resources also magnify other major material problems in the lives of families with disabled children. The families often find themselves living in housing conditions that are restrictive and unsuitable for both the disabled child and the parents (Sloper and Turner 1992). Given the lack of public financial assistance and the absence of suitable public housing, the families frequently experience great financial pressure due to moving house or undertaking adaptations at their own expense (Oldman and Beresford 1998). In addition, the rate of ownership of ordinary consumer items, such as cars and washing machines, given the additional demands of bringing up a disabled child, is lower among the families of disabled children than the general population (Baldwin and Carlisle 1994). For example, a national survey in the UK reported that only half of the families with a disabled child had access to a car, compared with two-thirds of those in the general population (Beresford 1995). When there are serious shortfalls in the public support designed to offset the costs of using special services, special equipment and other facilities to meet the child's needs, rearing a disabled child imposes great hardship in terms of managing the household budget, and other the family members' needs are often sacrificed. Some Korean research on families with disabled children has reported that, on average, a third of household income is spent on purchasing these

services or basic items that are essential to the children's well-being (Lee and Lee 2000; Yi 2003).

A consideration of these financial and practical problems encountered by families is important in its own right, but it is also important to be aware that these inadequate material conditions for rearing a disabled child frequently cause psycho-emotional damage to the parents. Research has provided evidence of a clear association between high levels of parental stress and concerns about their fragile financial position and other vital material assets (e.g. Beresford et al. 1995). Furthermore, restricted financial resources and other material problems can undermine the parents' attempts to engage in 'good parenting', and consequently damage their sense of morality and self-esteem as parents (Hillyer 1993).

Disabling services and professionals

Information is one of the most significant factors that impacts upon parents' ways of planning, managing their family life and coping with the problems that they encounter. In addition to general knowledge about child rearing, the presence of a disabled child demands that parents learn and absorb special kinds of information: this can be about the child's condition, welfare benefits, educational system, practical services to aid the child's development and other social services. While the parents' demographic and social attributes, such as their class and ethnicity, also influence the accessing of information, most parents commonly experience, throughout their life spans, substantial difficulties in identifying or obtaining crucial information (Beresford 1995; Sloper and Turner 1992). Recent studies have reported that many parents still have to make extraordinary efforts, which are both time-consuming and

stressful, to access basic information that is directly related to their child's well-being (Ball 1998; Read and Clement 2001).

In addition to the direct care work, parenting a disabled child necessitates contact with a number of specialist services designed to aid the child's development and secure the child's interests. Parents consistently argue that the presence of appropriate, supportive services is a significant factor that makes a very big difference to their disabled child's life, as well as their family as a whole (Darling and Darling 1982; Seligman and Darling 1997). It has been well documented that a good service that meets the family's needs is not only an important resource, helping them to cope with the practical problems in their daily lives, but also a powerful mediator of stress (Sloper et al. 1991; Todd and Shearn 1996). However, a range of studies reports that very many parents experience substantial difficulties in receiving appropriate, timely services. It has also been documented that there are substantial levels of dissatisfaction with the existing services, in terms of both in quantity and quality (Beresford 1995; Read and Clements 2001; Sloper and Turner 2002;). Indeed, obtaining the services that the parents perceive as necessary for their child's well-being is the most stressful part of bringing up a disabled child. For example, a UK national survey in 1995 found that about half of the parents complained that they 'have to fight for everything' that their disabled children need (Beresford 1995).

In addition to the problems of the unmet needs for services, the parents of disabled children have continually reported difficulties regarding the ways in which the services are operated and their relationships with the service providers. Stehlick's (2000) study of parents caring for children with intellectual disabilities in Austria over five decades identifies the parents' relationships with the health and other social

service professionals as 'sites of struggle'. She reports that, from the moment of diagnosis and across the whole of childhood, parents complain of a subordinate power relationship with the professionals. Despite the family-centred and family empowerment models that have been adopted by the health and social care organisations, research studies still confirm that parents identify their relationships with the professionals as unequal, non-collaborative and negative (Case 2000; Grant 2003; Murrery 2000).

Isolation and exclusion

It has been widely documented that disabled children and others in their families experience unequal opportunities to participate in mainstream social activities, and that they are frequently isolated from their peers and the wider community. Traditional research has explained this restriction of socialisation by exclusively focusing upon the child's impairment effects and the accompanying 'burden' of care. We should not overemphasise the child's specific impairment effects in considering their impact on the daily family management, because, as recent studies have shown, unequal opportunities to participate in 'ordinary' social activities are not simply attributable to a child's physical or behavioural problems; rather, they are shaped by economic, social and cultural contingencies.

In addition to the extra caring demands in relation to their child's specific mobility and behavioural difficulties, the parents of disabled children also consistently reported that the unavailability of appropriate care services and/or inaccessibility of mainstream childcare provision (e.g. nursery schools) is the most significant problem that constrains their aspirations for social participation. The

parents, particularly the mothers, are frequently compelled to withdraw from their previous social career and social relationships because childcare becomes the sole responsibility of the parent. In addition, transport problems, a restricted household income, and an inaccessible built environment have often been cited by parents as barriers preventing the family from participating in mainstream social activities. Most particularly, the restriction of financial resources constrains the possibility of engaging in leisure and other meaningful social activities that are taken for granted by others in the population. Together, these factors often make it difficult for disabled families - especially vulnerable groups, such as lone-parent families - to escape from their household and so lead to a feeling of 'being ghettoised' (Read 2000).

It has been widely illustrated within disability studies that disabled children encounter a variety of forms of exclusion and discrimination, ranging from negative attitudes to systematic segregation (Middleton 1999; Morris 1998; Shakespeare and Watson 1998). Social hostility toward disabled children also induces discriminatory responses towards other members of their family. For example, Atkinson and Crawforth (1995), in their study of 29 siblings of disabled children, reported that almost three-quarters of them experienced bullying or teasing at school. A number of studies of the experiences of the parents of disabled children have examined how the prevailing negative perceptions of their disabled children make the parents 'Others' – being treated by others as 'less than whole parents' and impose on them a sense of social isolation (Green 2003; Greenspan 1998; Gregory 1991; Landsman 1998, 1999). As Glendinning (1983:225) puts it:

The reactions of members of the public in the street and other public places, and reports in the press and on radio and TV all communicate to parents the

dominant responses of society to severe disablement in children. In different ways these messages seemed to lead to the development and reinforcement of a sense of social isolation: an awareness of the many ways in which their particular experience of parenthood diverged from the patterns of those around them.

Lay explanation schemes of impairment and disability

The recent developments in cultural studies on disability, especially by American anthropologists, have emphasised that the treatment of disabled children takes various forms across and within societies by interacting with other context-specific cultural beliefs and values (e.g. Armstrong and Fitzgerald 1996; Groce and Zola 1993; Ingstad and Whyte 1995; Sheer and Groce 1988). In particular, from the cross-cultural perspective, they have tried to explore how, and what kinds of, folk and lay theories are used to explain the presence of the impaired body/soul and influence people's perceptions of disabled children and their families. According to one widely used typology, the lay explanation schemes of impairment and disability can be examined as locating the origin: (a) within the individual; (b) in the natural world; (c) in the social world; or (d) in the supernatural world (Helman 1994, quoted from Armstrong and Fitzgerald 1996).

The individual-centred lay schemes place responsibility on the person concerned. For example, in India, the Hindu belief considers that being disabled is the inevitable result of previous bad conduct by the individual (Groce and Zola 1993; Hanks and Hanks 1948). Similarly, the Buddhist beliefs held by many Korean people convey the message that having a disabled child is the result of the sins that a parent committed in the previous life (Jeong 2001). It is also a feature of Western cultures to

attribute the child's disability to the parents' lifestyle and carelessness (for example, malnutrition, drug abuse) (Gregory 1994). The Chinese traditional cosmology, which is revived in current Chinese medicine (also in Korean medicine), offers explanations of disability in terms of an imbalance of opposing forces or loss of harmony within an individual's body (S. Lee 2001; Stone 1998).

Many Hmong (Meyers 1992) and Pacific Islander (Nicolaisen 1995) families impute having a disabled child to a 'natural' cause, such as the environment, old age, changes in the weather, drinking or eating unsuitable water or food. The explanations relating the child's disability to the natural world also ascribe socio-cultural meanings. For example, Malay folk beliefs hold a father's inappropriate interaction with the natural world (e.g. his cruelty to animals) responsible for his child's congenital impairment (Laderman 1987).

Lay beliefs that attribute the birth of a disabled child to the social world seek explanatory schemes from group phenomena or the parent's social interaction with others. For instance, many Songye families believe that a child's disability is a response to disharmony in the relationships among kinship members; the father of a disabled child often asks his wife to redistribute her dowry among the kinship members to restore harmony (Devlieger 1995). Lay beliefs in many societies (including Korea) attribute a child's disability to interpersonal conflicts, especially a mother's conflicts with her family members or others during pregnancy (Armstrong and Fitzgerald 1996).

The placement of the causes of a child's impairment in the supernatural world may be most common and prominent in lay beliefs across societies, connecting disability with 'sin' and perceiving it as supernatural punishment (Armstrong and

Fitzgerald 1996). Devliger (1995), in his cultural analysis of childhood disability, cites the African belief that, if the ancestors are not given their due respect, their spirit may return as a disabled child for retribution. Similarly, the traditional lay belief recurs in Korean society: having a disabled child or the acquisition of impairment is caused by a parent's neglect of ancestor worship; for example, when burial practices or ceremonial activities are conducted in an inappropriate way (Choi 1994, 1997).

Cross-cultural studies on the perception of impairment and disability, above all, have provided the chance to rethink the (Western) positivistic and individualised notions of disability. Even though it is the trend to attribute meanings of misfortune and stigma to impaired bodies across societies, such practices do not always operate on the atomistic, individualised body (Groce and Zola 1993). Instead, various 'relational explanation schemes' of impairment in accordance with a holistic view are also widely recorded (Whyte and Ingstad 1995). Furthermore, as theorists of disability underline, interpretations of disability are always interwoven with other cultural and sub-cultural values, whether they function to reinforce stigma or alleviate it; whether they facilitate the segregation of disabled people or mitigate it (Devliger et al. 2000; Hershenson 2000).

In exploring parents' experiences of disability, I will adopt many of the insights provided by these cultural studies. At first, taken as a whole, various lay beliefs about and explanations of impairment can be considered as a complex body of disability knowledge operating in everyday lives. People's explanations of disability typically involve reference to an 'etic-emic mix of modern biomedical and philosophical, religious, cosmological and traditional folk elements', the latter of

which particularly involves interpreting ‘why’ questions – for example, why this person? why this form of impairment? (Armstrong and Fitzgerald 1996) Thus, paying attention to lay explanatory schemes is useful in investigating how and what cultural interpretations are operating among parents or being operated by others towards their disabled children. Secondly, cultural and sub-cultural explanations of disability are neither given nor fixed. They may not only vary across individuals and groups but also change over time. Thus, paying attention to the changes in the lay explanations about disability may provide a lens through which to understand how the social conceptions of disability are formed and transformed. For example, one activist in a parents’ organisation noted that one of the most significant changes in Korean parents’ perception of disability was that they began to break free of the traditional thinking that conceives a disabled child as a ‘blemish on the family’s name and status’ [from my informal meeting in 2002]. Finally, at the individual level, the parents of disabled children may draw on various cultural and sub-cultural values (e.g. religious beliefs, family values) to create their narratives about their children and make sense of their social positions, roles, responsibilities and identities. My concern lies in exploring what kinds of cultural sources parents draw on in creating their self-definitions of disability and how they are used in the parents’ constitutions of parenthood and political-normative interpretations of disability.

DISABILITY-PARENTHOOD AND PARENTS’ POLITICS OF DISABILITY

In the previous section, I argued that research on parents with disabled children needs

to: (a) give more weight to the parents' own accounts of their lives beyond a pathological presumption; (b) pay attention to the disabling conditions in which the children are parented; and (c) acknowledge the parents' experiences with regard to the social and cultural contexts in which they are embedded. This section proceeds to discuss the parents' embodiment of disability and their practices from a socio-political perspective, paying particular attention to their struggles within and against the disabling society.

Disability-embodied parenthood and disability work

Inequalities based on disability add to the complexities of the family dynamics and challenge many of the assumptions about parenthood and parenting. Given that society is designed for non-disabled people, parenting a disabled child is not like parenting a 'normal' child. Kittay (1999), a feminist philosopher and mother of a daughter with a severe impairment, draws attention to particular features of disability-parenthood by re-examining what is commonly identified as essential parental work – that is, preservative love, socialising the child for acceptance, and fostering the child's development. Regarding preservative love, she notes that the parental responsibility to preserve the severely impaired child's life is often accompanied by a life-long commitment to his/her day-to-day physical care. The protracted dependency of the child can be a threat to the 'normal' phase of parenting. However, as she underscores, this alteration of the parents' life course is a product of an able-body (or -mind)-focused society, where dependency (and the distribution of care work) is omitted from considerations of social justice. In relation to socialising

the child for acceptance, she addresses the double-sided nature of the parents' activities. The parents of disabled children have not only to encourage their child to prepare for a world larger than the family, but also to 'socialise the world' so that it will accept the child despite his or her difference. Finally, she points out that parenting a disabled child entails the work of 'enabling' as well as fostering the child's development, because the development of many children with severe impairments is not given. This demands that the parents of disabled children undertake more 'specialised' or intensive parental work (such as absorbing professional knowledge) than the parents of non-disabled children, and the task of dealing with health, education, and other professionals constitutes an integral component of their work.

Some scholars have paid attention to the new or extended roles that the parents of disabled children have to fulfil in order to secure their child's welfare. Darling (1988) notes that parents adopt an 'entrepreneurial role' when they continue to encounter needs that cannot be met by the existing societal resources. This role includes seeking information, seeking control and challenging authority. In her recent study of 12 mothers in England, Read (2000) explored the 'mediating role' of mothers who acted as 'buffers' between their children and various professionals and institutions. She argues that the job of mediator became an almost inevitable extension of their roles as parents under social circumstances that are unfavourable to disabled children. She writes:

As they modify and augment their views about their children, their children's place in the world and the need to safeguard their interests, they find themselves increasingly and irrevocably drawn into the role of go-between and the buffer state. Many do not take to the role easily but feel that they

have no alternative.

(Read 2000: 115)

In their study of the mothers of children with profound impairments in Canada, Mackeever and Miller (2004) also explored the multiple roles and tactics that those mothers had to develop over time, including the manipulation of the child's appearance. By eliciting the mothers' perspectives and meanings, they found that these parental practices were a kind of strategic invention to enhance the children's social position and augmenting resources in many fields of social life.

Several authors have attempted to explicate the terrain of the parents' practices in terms of careers that they have embarked upon in trying to get their own children's needs met, which then broadened into disability work (Darling 1988; Traustadottir 1991, 2000; Wickham-Searl 1992a, 1992b). For instance, Traustadottir (2000) categorises the activities through which mothers extend their caring beyond their child to embrace advocacy and lobbying, and argues that this work is more like that associated with a professional career than traditional motherhood. Similarly, in her study of 14 mothers of disabled children in the USA, Wickham-Searl (1992a) reports that the mothers initially devoted their lives to their own children's welfare, but gradually extended their roles to assist other families in similar circumstances and to conduct other disability-related public work.

Transformative experiences

When the existing literature is explored in an effort to discover what is known about the lives of the parents of disabled children, one immediate problem presents itself.

While there are exceptions, researchers have tended to focus primarily upon the seemingly negative results of having a disabled child. Scorgie (1996) argues that, in the professional literature, ways of interpreting the reactions and behaviours associated with parenting disabled children have been biased due to two fundamental problems. Firstly, sharing one's life with a disabled child is predominantly described in terms of coping with stress, which is informed by the notion that the lives of families with such children are characterised by a deficit. Secondly, investigators have conventionally examined only short-term responses, assuming that negative initial reactions and behaviours evident at certain crisis moments constitute the overall picture of the lives of the parents of disabled children. By eliciting the parents' perspectives, Scorgie argues that, in order to understand how parents manage their lives, one has to include the potential benefits of being involved in such a task and the transformational outcomes they experience:

In fact, parents seemed to be describing their experiences as a journey – a journey from the devastation which accompanied the initial diagnosis to a place where they were beginning to discover, and often to their surprise, not only that they were able to manage life effectively, but they were also being enriched along the way. Thus, the focus of the study broadened to include, not just life management strategies, but transformational outcomes.

(Scorgie, 1996: 7)

In a recent study, Scorgie and Sobsey (2000) identify a range of transformational outcomes associated with parenting disabled children. Their research suggests that parents perceive personal transformations in terms of acquired roles or acquired traits, relational transformations regarding family, advocacy, new friendship networks and attitudes towards people in general, and finally perspective transformations, which

refer to changes in attitudes towards life and acquiring a different view of living with a disabled child. Citing Pauls (1993: 53), they argue that, although challenging events or circumstances tend to produce negative results initially, 'positive outcomes are usually slower to be realised, enduring and of a higher order' (for instance, a change in values or the ability to form satisfying relationships).

Several writers have also suggested that, in order to understand how parents regain their strength and resilience against a background of social barriers and restricted circumstances, one has to appreciate the transformative experiences that they undergo over time and consider these experiences as a crucial part of the development of disability-parenthood (Greenspan 1998; Landsman 1998, 1999). The writings of parents of disabled children themselves certainly support this line of approach (e.g. Bérubé 1996; Curry 1995). Parents frequently describe living with a disabled child as a 'journey' to emphasise their on-going process of learning from and sharing with their disabled child. According to their stories, the goals of parenting a disabled child is not simply to adjust their child and themselves to the existing social arrangement; nor is it to follow certain principles of 'normalisation' that society imposes (Hillyer 1993). In the process of continually encountering circumstances that they regard as unfair to their children and struggling to secure their children's welfare, many parents come to develop moral-political judgments about the social treatment of their children and to forge their identity as 'allies' of their children to enhance the children's position in society (Murray and Penman 1996; Read 2000). The following parent's narrative captures the essence of such parental transformative experiences:

We are learning that the journey begins in our homes – in our own lives. We are learning to challenge the set of beliefs we grew up with. We are learning about being allies to our children. We write from a human rights perspective. We do not accept the medical or charitable models of disability which present our children as defective. They are models which we, as parents, are expected to accept and collude with against our children. To collude in this way would mean seeing our children in the negative way society at present sees them. This would fundamentally damage our families...Our children are the ones who teach us about the issue. They give us the opportunities to learn and understand. They give us determination and confidence...Our children are teaching us how to be their allies.

(Murray and Penman 1996: ix)

Read (1991, 2000) also emphasises that parents should not be seen simply as a passive conduit for handing down socially acceptable values. She argues that it is helpful to see parents as ‘active subjects’ who are involved in interpretive processes. On the basis of her own research on mothers’ experiences of rearing disabled children, Read (2000) argues that, as they get to know their children, parents learn to see their difference in novel ways, which generally changes their prior perceptions of disability, and reconstructs their identity beyond the prevailing notions of ‘normal’ parenthood. She also suggests that parents develop critical understandings of their own and their children’s problems as part of their every day experiences of inequality and injustice. Through these processes, many parents gradually change their views of the world of disability:

In their own particular ways, in their own words and as their own pace, very many start to make a distinction between their child’s impairment and the negative things that all too often go along with it in our contemporary society. Women become convinced through their own experience that many of the most restrictive features of their own and their children’s lives are not an inevitable or necessary consequence of having impairments.

(Read, 2000: 117)

Self-help groups and parents' disability politics

A self-help movement among parents emerges, above all, from their daily experience of discrimination as nurturers, carers and parents (Dybwad 1990). Encountering an injustice at first hand, or experiencing barriers to ensuring their children's welfare, the parents of disabled children seek ways to do something positive and this sometimes brings them into contact with find similarly-situated people in their efforts to bring about change. Shared issues or problems motivate parents to collectively to respond to the problems they face, and foster their sense of community.

According to most definitions, a key ingredient in any parents' self-help movement is mutual support. By forging support networks between participants, through either face-to-face interactions or virtual relationships, parents give and receive a range of resources and help to cope with the problems that are overlooked by the existing social institutions. As a number of researches illustrate, the emotional and practical support offered by parents' self-help groups greatly enhances the participants' perceptions and feelings about themselves; their knowledge and self-confidence when dealing with medical, educational, and other professionals; and their mental well-being (Pizzo 1983; Seligman and Darling 1997; Solomon et al. 2001). Few would deny that the community-building and positive identities offered by self-help groups, combined with the emotional bonds and unconditional acceptance, are a source of both individual and collective empowerment (Taylor 1996). As Hillyer (1993) notes, many parents find that this helps to overcome their feelings of isolation and free themselves of feelings of 'internal oppression', such as self-victimisation and self-blame.

Another important role of parents' self-help groups is to facilitate the parents' politics of disability. As Fraser (1997:81) notes, the community or networks that subordinated groups forge can serve as a 'subaltern counter-public' where they 'invent and circulate counter-discourses, which in turn permit them to formulate oppositional interpretations of their identities, interests and needs' When parents gather, they realise that they share many of the same issues and concerns, validating their experiences and come to develop their own explanations of, and solutions to problems based, at least in part, on everyday experiences (Pizzo 1983). Parents' groups can serve as a kind of classroom in which 'cultures of resistance and everyday forms of resistance are learned' (Collins 2000). When they interact with others, parents hear others' stories of advocacy and learn about techniques that worked, coming to realise that authority can be successfully changed (Seligman and Darling 1997). Group advocacy can also act as a catalyst for parents to take collective action to change the environment. Wolfensberger (1973) observed that parents take collective action in four major areas: the provision and obtaining of services; the acquisition of public funds; monitoring services; and educating the public.

Parents' self-help groups can be considered as a site in which a sub- or counter-culture is nurtured. Rapp (2000: 290) notes that, through sharing life stories, parents collectively develop and transmit 'a worldview in which difference could be accepted and a new identity as parents of a different kind of child could be formulated and assumed'. This particular 'collective journey' not only provides potential resources to challenge the externally defined, controlling images of disabled families, but also facilitates the construction of a sense of community and collective

pride.

CONCLUSION

This chapter has discussed various theoretical definitions and interpretations of disability and has highlighted the social, systematic operation of disablism and its oppressive features. It also discussed the dominant disabling values, cultural practices and their ideological effects in justifying disabling social relations. It then provided a brief overview of the research trends regarding families with a disabled child over the last few decades and examined some of the central themes that have emerged from the research in the light of the disabling condition of parenting a disabled child. It was suggested that research on the parents of disabled children needs to go beyond the traditional, pathological approaches and consider the wider social and cultural milieus in which they are embedded. In the last section of this chapter, I explored the literature that documents the characteristics of disability-parenthood and discussed the parents' practices from a socio-political perspective.

The subsequent analysis of the parents' experiences and practices will be based not only on the theoretical frameworks discussed so far, but also on data generated by the research. The next chapter will discuss my chosen methodology, research process and data generation strategies in detail.

CHAPTER THREE

RESEARCHING THE EXPERIENCES AND PRACTICES OF PARENTS WITH A DISABLED CHILD IN KOREA

INTRODUCTION

This chapter is divided into two parts. In the first part, I provide a brief overview of disability problems in Korea, including the historical dimension. The second part of this chapter deals with the methodology, research practice, and process of data collection and analysis. It starts with considerations of the ontological and epistemological stance adopted in conducting this research, followed by an explanation of the fieldwork process and associated activities, such as the methods and techniques used for the collection of relevant data. It finally discusses the approach to processing and analysing the data generated.

CONFIGURATION OF DISABILITY PROBLEMS IN THE KOREAN CONTEXT

The historical emergence of modern forms of disablism

It has been noted that the emergence of the systematic segregation of disabled people from other population groups in the Korean context was highly interwoven with the social transformation occurring during the period of Japanese colonisation (Jeong 1997, 2001). Japanese colonial rule between 1910 and 1945, with its general goal of extending the economic market and exploiting natural resources, implanted a capitalist mode of production and imposed disciplinary working norms across all economic sectors - a pattern which has been termed 'harsh-extreme labour exploitation' (Eckert 1993).

As far as disabled people are concerned, two significant features should be noted. Firstly, the social categorisation of people on the basis of individual physical functionality became dominant. Somewhat culturally blurred notions of physical limitation in the previous era were manifested in a monolithic way through the dualistic gaze of 'productive/non-productive'. Consequently, disabled people began to be excluded systematically from the sphere of economic production (Jeong 2001). This was a significant change considering the fact that people with impairments had generally participated in a variety of production activities (including agriculture) in the pre-modern period (Im and Song 1996).

Secondly, disabled people began to be distinguished from other social groups on the grounds of their impairment and marginalised as 'undeserving' groups in the population. As Korean scholars note, one of the principal characteristics of the trends in the literature in the period of colonisation was the use of disabled people as a metaphor to describe the changing societal situation and values (see Choi 2001).

Disabled people were typically depicted as a 'useless' and 'inferior' group, incapable of surviving in the changed social conditions or vanishing historical circumstances (Choi 2001). Of course, assigning negative meanings to disabled people (e.g. 'stupid' and 'sinful') was also evident in traditional Korean societies (Choi 1994). However, such cultural meanings surrounding impairment had always been contested because they intersected with various cosmological philosophies, religious and folk beliefs (Choi 1997; Park 1999). Indeed, positive interpretations of impaired bodies (for example, as a mediator of community harmony, or the embodiment of a new cosmological order) were also the critical components in the cultural perceptions of disabled people (S. Lee 1999). Furthermore, Korean pre-modern history contains some counter-evidence to the presumption that disabled people were always located in the lowest, or at best, a marginal social status. The case of blind people provides a remarkable counter example against such a myth. They had not only undertaken various social roles (for example, as fortune tellers, story-tellers, bureaucratic educators and Kingdom musicians) in pre-modern societies but also often entered the realm of high-level officialdom in the state (Oh 1988).

The strict socio-cultural separation of disabled people from other groups in the population was accelerated by another significant social transformation; that is, the breakdown of the traditional community values and village-based support networks (Moon 1996). Some Korean historians argue that, during the period of the Yi Dynasty (1392-1910), disabled people were treated no differently from other groups who needed help or care, such as elderly widows, orphans, or older, childless people (Im 1986; Im and Song 1996). Furthermore, the folk tales and the literature written in this period show that the presence of disabled people was considered a

community responsibility. Caring for disabled people, including feeding and dressing them, was frequently undertaken by village members and perceived as an integral part of community life (Choi 1997). Such a 'relational' perception of disabled people dramatically disappeared alongside the rapid spread of capitalist production rhythms and norms (Yu et al. 2002). After that, as one novelist recounts in the stories of his own village, disabled people became invisible in everyday interactions: they were sent to the newly emerging institutions or confined to the family home (Yi 2000).

In addition, colonial medical policy adopted a eugenics approach, which was a significant factor in constructing the dominant view of disabled people. As discussed by Foucault (1980), the medical knowledge/power embedded in colonial policies functioned to classify the colonised population and control the production of 'efficient bodies'. Disabled people, especially those with deformed bodies and mental impairment, became a primary target for institutionalisation with strict controls on their reproduction. It is reported that the sterilisation of disabled people was widespread and compulsory in the colonial state (Hong 1997; Jeong 2001).

So far, I have discussed the historical emergence and manifestation of modern forms of disablism in Korea. Rather than romanticising pre-modern societies, my concern has been to emphasise the 'historicity' of the construction of the modern perceptions and treatments of disabled people. To summarise, the construction of disablism and its practices through the period of colonisation resulted in significantly unfavourable social changes for disabled people, including: (a) the demise of the 'relational' perception of disabled people; (b) strict boundary-making between disabled people and non-disabled people through the imposition of the values of 'productivity' and 'efficiency'; and (c) the systematic exclusion of disabled people

from participation in social activities.

Two main social mechanisms to reinforce disablism in the development of Korea

It can be argued that the dominant disabling perceptions and practices constructed in the period of colonisation have been reproduced throughout modern Korean history.

Furthermore, in the process of national development in Korea after World War II, the segregation of disabled people from social activities tended to be reinforced and legitimised. Disablism frequently overlaps and intersects with other social oppressive mechanisms and ideologies (Lloyd 1995). Within the Korean context, two significant social features need to be discussed further: ‘national-developmentalism’ and ‘(neo-Confucian) familialism’.

‘State-led developmentalism’ (1960s-1980s) has been identified as one of the most distinctive characteristics in Korea’s rapid economic development and modernisation process (Haggard 1990; Wade 1990). In a general sense, it can be characterised as: (a) concentrating first on economic development whatever the cost; (b) emphasising the state’s leading role in the accumulation of capital and direct intervention in, and control of, the economic sectors; (c) maintaining coercive labour relations; (d) repressing democracy and social movements; and (e) utilising nationalism and anti-communism as political legitimacy (Koo 1993; Koo and Kim 1992). Further discussion of all these factors is beyond the scope of this thesis, but I will elaborate on how the state’s developmental project has reinforced the segregation of disabled people from mainstream society.

First of all, insofar as the state has concentrated on speedy economic

development, the political discourse of the 'maximisation of productivity in a national level' had been the hegemonic ideology (Koo 1993). This political discourse was also supported by the majority of Korean citizens who had experienced extreme poverty and national insecurity through the period of colonisation and the Korean War (1950-53). Subsequently, the debates on welfare seldom entered the public and political sphere. Social investment in welfare programmes was regarded as impossible at the initial stage of economic development and as a barrier to national capital accumulation (Yu et al. 2002). It is easy to understand that, in this general social trend, social support for disabled people and their families was not considered as an important public issue.

Secondly, in an indirect way, disabled people have been highly devalued in terms of their lack of national citizenship. In the process of Korean development, to secure healthy, productive and efficient bodies was one of the state's main projects under the name of modernisation, as implied by such popular slogans at the time as: 'No work, No food', 'A sound mind exists in a sound body', and 'Physical body strength is national power'. In summary, the physically healthy body was an unquestionable prerequisite for national citizenship (Jeong 2001). Disabled people were often regarded as an 'impurity' in the national population. On this basis, the state government argued that infants of mixed blood (inter-racial children) should be placed in the same category as disabled people, implying that they are 'abnormal' and 'impure' components of nationality (Moon 1996). Such popular thinking was frequently embodied in the state's intervention in population control. In the name of 'The Law of Mother's Health', avoiding the birth of a disabled child was one target of the public health policies (Hong 1997). In this general social context, disabled

people were to be ignored, if not eradicated.

In Korean society, familialism has been identified as a primary ideological mechanism in reproducing social orders and relations (M. Choi 1999). As many Korean scholars have argued, the traditional values of Confucianism which locate the family as a founding unit for social arrangements and the privileged contribution of the family as a civic virtue have been crucial barriers to the development of social welfare policies (Yu et al. 2002). Most especially, caring for dependants (e.g. older people and ill family members) has been widely accepted as a family responsibility. In this context, the problems of both carers and disabled people have seldom been approached from the perspective of citizenship rights. For the purpose of my research, the familialisation of disability problems is highly significant because it has been the strongest ideological norm that governs parents with disabled children. However, it is now being actively questioned and challenged by many parents in contemporary Korean society.

Turning points: the emergence of a disability movement

The emergence of a disability movement is a recent social phenomenon in Korea. Whilst there were some forms of collective action opposing discrimination against disabled people in the 1970s, it is generally agreed that the politicisation of disability problems took off in the late 1980s (Kim 2004). A key driver for change was the 1988 Seoul Paralympics. The staging of this event led to the major disability organisations and activists focusing public attention on the lack of government provision for the income and employment needs of disabled Korean people. Disabled

people's political campaigning and rapid mobilisation during the period of the Paralympics played an important part in the national government's decision to introduce the 'Law to Promote the Employment of Disabled Persons' in 1991.

The disability movement of the 1990s, based on the rapid growth of disabled people's independent organisations and nationwide alliance, achieved great advances in terms of their political power, which forced the state to respond to the claims of disabled people and implement welfare policies for them (Kim 2004). From 1995, the government began to respond to the demand to provide appropriate voting facilities for disabled people. Disabled people's long, direct action campaign for the right to mobility achieved the enactment of the 'Law for the Promotion of Facilities for the Disabled, the Old and the Pregnant' in 1997. In the 2000s, more diversified issues, such as disabled women's rights were raised, and the independent living movement proliferated (Kim 2005). On the basis of those achievements, the Disability Discrimination Act Solidarity Movement, which consists of 58 disability organisations, produced a draft legislation, entitled the 'Disability Discrimination and Enforcement Act'. This was submitted to the legislative body in June 2007.

The emergence of the parents' disability movement was also a remarkable development. Even though parents' organisations had been established in the 1980s, they were very small in number and usually operated by professionals. From the late 1990s, Korea witnessed the rapid growth of parent-led organisations, and their collective actions, especially for the educational rights of disabled children, began to become visible in the public sphere.

CONDUCTING THE RESEARCH

Ontological, epistemological and methodological considerations

The researcher's ontological and epistemological questions are central to the process of research because they provide the foundation for designing the research strategy and choosing the relevant methodology and methods (Harding 1986). With regard to disability research, the way in which such ontological questions as 'what is the nature of disability?', 'how does disability exist?', and 'what is the reality of being disabled?' are answered will identify certain objects as worthy of study over others and shape the research agenda. For instance, if disability is viewed as residing in the individual, then the research will focus on either reducing or rehabilitating the functional incapacity (Rioux 1997).

In conducting my research on parents with a disabled child, 'the social model of disability' serves as an ontological basis. Above all, I rejected the essentialist assumption that disability is a natural or pre-social phenomenon that is predetermined by biological factors. Instead, I adopted a social constructivist stance towards disability: disability problems are socially constructed and they arise as a result of social processes and the interaction of social forces. An emancipatory notion of disability was also central to my understanding of the subordination and resistance of disabled people and their families. For me, the world of disability was defined as the socio-political terrain in which specific forms of oppression are manifested and that these should be reconfigured through active resistance.

This critical, social constructivist paradigmatic understanding of the reality

of disability prompted me to conduct research on families with a disabled child in a manner that differed from the dominant research trend, which is shaped by 'psychological' and/or 'therapeutic' frameworks (Read 2000). Many ideas about the solution of disability problems are filed in the category loosely called 'adjustment literature', which focuses upon the personal/family qualities of those defined as being or having the problem (Linton 1998). The policy derived from that research centres on remedying or 'fixing' certain types of personal/family attitudes, behaviours and functioning that are identified as 'maladjustment'. As a result, the difficulties of parenting a disabled child have been traditionally relegated into the 'private' sphere. In contrast, this research aims to reinterpret 'personal/family troubles' as 'public issues' by exposing the material, social and cultural contingencies that shape the problems. This intention led me to approach the problems of disabled children and their families from the perspective of social justice and citizenship rights.

I also adopted a critical stance towards the anti-agency tendency embedded within the professional research on the parents of disabled children. Although there are exceptions, such parents have been conventionally conceived as being victims or the passive recipients of tragedy. Consequently, the parents' struggles against the disabling social forces and barriers have seldom been translated into academic knowledge about the experiences of the parents of disabled children. I sensed that the reluctance to pay attention to those parental practices is another way of perpetuating the idea that parenting a disabled child is a private, domestic, therapeutic matter, and, at the same time, of depoliticising parenthood and disability. In contrast, my conducting of this research has been based upon the belief that the parents' personal

and/or collective struggles to transform their situation are a central aspect of their parental practice. By extending our understanding of parenting a disabled child into the public and political domains, this study also aims to relocate the parents as a force for social agency and a political subject.

An epistemology is a theory of knowledge. It answers questions about who can be a knower, what can be known, and what constitutes and can be legitimated as knowledge (Mason 2002). Disability writers have been highly critical of the way in which disabled people and their families have been marginalised as knowers and seldom identified as producers of knowledge (Moore et al. 1998; Oliver 1992; Zarb 1992). I was also alarmed by how much the parents' self-knowledge, grounded in their lived experiences, had been excluded by traditional research. As a disability research project, one of the basic goals of this study was to bring the parents' experiential knowledge into the realm of knowledge production.

According epistemological privilege to experience in knowledge production was highly recommended by disabled feminist writings (Crow 1996; Morris 1992, 1996; Thomas 1999). I considered that personal experiences and accounts could be used as analytical tools for exposing the social nature of disablement. As Thomas (1999) aptly states:

In opposition to [the] view that a focus on individual lives and experiences fails to enable us to understand (and thus to challenge) the socio-cultural, I would agree with those who see life history accounts...as evidence 'the micro' is constitutive of the 'macro'. Experiential narratives offer a route in to understanding the 'socio-structural'.

(Thomas 1999: 78)

Morris (1992) addresses the personal experiences of individuals portrayed through

research and how these can become political, since they give a voice to the less powerful groups in society and so help to challenge oppression and barriers to greater equality rather than adding to them. I wanted to emulate this goal by collecting personal life stories and examining the participants' experiences in conjunction with the material and cultural conditions within which their lives were embedded. I also wanted to contribute to the growing parents' movement that claims the right to interpret their lives in their own terms. Giving voice to the parents is the first step towards achieving this goal, particularly in terms of challenging deficit-based and pathological representations of disabled families.

Personal preparations

Traditionally, what a social scientist brings to a research project from his or her personal background, experiential knowledge or beliefs has been treated as 'bias', and therefore something to be eliminated. However, there has been growing recognition that the researcher's subjectivity cannot be separated from the research process, or even from the analysis and presentation of the research findings (Guba and Lincoln 1994). A number of writers have suggested considering personal preparation (including the critical examination of value premises) as an integral part of the research process, encouraging researchers to view their own subjectivity as a valuable component of the research, rather than something to be suppressed (Glesne and Peshkin 1992; Maxwell 1996).

As I reflected during this research project on parents with disabled children, it became clear that it was substantially shaped by my personal experiences,

intentions and hopes as well as well as by the spirit of academic inquiry. Above all, this research was initially motivated by my growing sense of shared experience with the parents of disabled children. Even though I am not a parent of a disabled child, my own experience of living with a disabled younger brother for about fifteen years served as a kind of reference point in giving meaning to the research and developing the research enquiries. Many parents of disabled children describe their lives as a 'journey', and I also realised that living with my younger brother taught me many things that I did not know before, greatly changing my previous perceptions and understanding of the world of disability. Whilst I had not held a highly negative perception of disabled people previously, I had grown up with little contact with this group and had been socialised to a set of disabling values. I perceived that the presence of a member with an impairment was as 'unfortunate' family event and identified my role as helping him to rehabilitate his loss of physical functioning as far as possible. However, experiencing a number of barriers in the course of meeting my brother's needs and continually encountering day-to-day difficulties gradually changed my perspectives towards disability problems. Getting to know the reality of other disabled people also led me to reformulate my identity as an ally of disabled people, and I became engaged in disabled people's organisations and the collective movement for change.

In reading the writings of the parents and talking with them, I felt that, despite our different roles, we shared similar experiences, especially in terms of disablement and the reappraisal of our previous thoughts on disability. This was the initial motivation to conduct a parents' experience-focused research study. In addition to the desire to expose the inequalities and exclusion that families with

disabled children experience in Korea, I was very interested, both personally and academically, in how parents make sense of living with a disabled child (in a new way) and how they develop their parenthood in the course of the interplay between their child and the disabling society.

My interest in the parents' experience of disability and their practices expanded into the arena of their collective activities as I became aware of the emergence of parents' groups in Korea. In particular, in the period of my pilot research (in 2002), I had the opportunity to participate in a parents' gathering and to talk with some of the founder members of the parents' groups. Their hope, energy and sense of mission made a strong impression on me and raised a number of research questions: Why had they come together? What did they want to achieve and develop by working together? In this process, I also expected that making parents' group activities visible would help to change the perception of disability and facilitate the empowerment of disabled families, at least in Korea.

In terms of my personal academic aims, I wanted to enrich the field of disability studies by extending the analysis of disability to those close to disabled people. A related desire was to bring the rights of the 'dependent worker' (specifically, the family members) and disabled people together in theorising about disability politics and the disabled people's movement, which had hitherto been discussed separately (Shakespeare 2000). In retrospect, this was a further motivation for conducting the research on the parents of disabled children and designing the research within the intellectual and political heritage of disability studies.

Relationship between the researcher and the researched

How do I position myself in relation to the researched? What kinds of roles can/should I play in conducting the research? What kind of relationship between myself and the participants is desirable in terms of the knowledge production? These are questions I have to ask in conducting the research and examine continually during the period of fieldwork. Here, I want to discuss some of the ethical and political issues that were raised in forging relationships with the researched.

First and foremost, I wanted to eradicate the traditional distinction between the researcher and the researched. I endeavoured to place the participants at the centre of the research process in the belief that true knowledge can be produced only when the researcher and researched act as collaborators or co-researchers. As illustrated in the section on 'methods', I tried to reduce my role as a traditional investigator (who is supposed to ask only predetermined questions) by purposely giving the participants the authority to decide what they wanted to express and what was important to them. Tactically, in my interaction with the participants, I positioned myself as a 'learner', frequently saying 'I believe you are more expert than anyone else in talking about the problem of disabled children and their families'.

A number of disability writers suggest that researchers are required to take the issue of reciprocity seriously in the research process. Oliver (1992) addresses the problem that, within the traditional social relations of research, researchers do not reveal as much about themselves as do the research subjects. Barnes (1992b) and Vernon (1997) emphasise that, in order to secure a workable dialogue, the researcher should make his or her intentions, values and motivations explicit and be prepared to answer direct questions that may include the exchange of personal information. In

my research, reciprocity was a prerequisite to developing a rapport with the participants and was one of most significant factors facilitating the parents' active participation in knowledge production. In the process of the research, I noticed several times that my role as a researcher shifted to that of the one being investigated. Many of the parents also wanted to know about me and why I was interested in disabled families and parents' groups. I tried to give them transparent information about my personal background, motivations, and desires (including my own stories of living with my disabled younger brother and reasons for studying in the UK) as well as the research purposes. Indeed, the rapport developed with the participants occurred as a result of my being willing to share information with them. It also had something to do with the degree of trust and/or openness that I received from them.

Another central concern throughout the research process (and even in writing the thesis) was the risk of misunderstanding the participants' experiences and accounts. Whilst I attempted to place the parents at the centre of the research process and analysis, it was inevitable that I, as a researcher, would re-interpret their accounts by reference to my own ideas, values and theoretical frameworks. I often realised that I had made erroneous judgments about the parents' accounts of their life decisions or certain behaviours due to my lack of deep understanding about the specific concrete situations in which they were situated. Thus, the promotion of 'self-reflexivity' was very important in order to overcome such unintended distortion, and to establish what they 'really' meant. I tried to solve the problem by making efforts to immerse myself in their world (through a long period of participation) and to augment my opportunities to discuss issues raised with parents in the everyday research setting, especially with those in the APCCP.

Another question that arose about my relationship with the participants was whether I could play certain contributive roles for them. As the research progressed, I came to think that my research practice itself could be utilised as a way of promoting the empowerment of participants. For instance, when interviewing the parents in the SAPHRDP, they wanted to get to know other parents' groups I had already contacted, as they hoped to learn something from their experiences. I introduced Dong-keun, a research participant who had been involved in parents' group activities for a long period, to them and helped to arrange a talk by him on his group's activities. Whilst this kind of involvement might not be directly related to my research, I saw it as an extended role that I had to undertake and also a way of fulfilling the participants' sense of achieving mutual benefits.

The research process

The fieldwork to collect data spanned a period of twelve months, beginning in September 2003 and continuing until August 2004. Activities during this period included the qualitative interviewing of twenty-nine parents of disabled children, participant observation of their groups' activities, collecting relevant documents and literature and keeping field notes.

In a broad sense, the fieldwork consisted of three phases. Before entering the world of the researched, I planned to conduct a case study of parents in a single self-help group, 'The Association of Parents of Children with Cerebral Palsy (APCCP)'. I thought naïvely that I would be able to access the group without difficulty and recruit interviewees from within its ranks because I had known some of its founding

members and had conducted pilot interviews with two representatives in 2001. However, when I contacted the group again regarding this research, I realised that the APCCP had undergone many changes. The membership had increased, and it had developed some 'formal' organisational characteristics: for instance, three hired staff members were working full-time and the group was running various organisational programmes, including service provision for its members. Furthermore, the representative members I had known before had ceased their involvement in the group's activities due to personal or family problems.

These changes positioned me as a stranger to the group and required that I should rebuild cordial relationships with the members. Dong-min, who was a leader at the time of the fieldwork, played a gatekeeper role, enabling me to get to know the leading members and participate in the group's activities. As he grew to trust my intentions and the research project through several candid and searching conversations, Dong-min invited me to the monthly meeting of the board members and set aside a time to talk about my research. During the meeting, I explained broadly my personal motivations to study families with disabled children, my reasons for being interested in parents' groups and the goals of the research. The parents were supportive of my research and appreciated my intention to make the problems of disabled children and their families visible. Supported by the leading members, I was allowed to work regularly at the office of the organisation: this comprised two days per week from November 2003 until May 2004.

I saw my regular presence working at the organisation as providing an open door that enabled me to get knowledge about the parents' world and the community. While it was clear that my participation was research-related, the decision to work

there was also guided by my thoughts on the relationship between the researcher and the researched: I hoped that my continual contact with the parents would help or benefit the development of the group in various ways. My experience of working at the APCCP provided an invaluable opportunity to learn to see the parents' world from their perspectives as well as developing cordial relationships with the parents in the community. Most importantly, through my continuing encounters with them, the initial concerns of some of the parents that my participation would simply benefit myself alone was gradually transformed into an expectation that my research would contribute to representing their experiences and problems in an undistorted way. I also observed that many of the parents in the group started to treat me as one of their community and a 'co-worker' who shared the goal of improving the social conditions of disabled children and their families. On the basis of a growing sense of trust in our relationship, many of the parents expressed a willingness to share their personal life stories about rearing a disabled child. The stories that they told in the course of our chats helped me to understand better the concrete reality of their lives and grasp the salient aspects of the problems they experienced. It should also be noted here that the openness they showed during these conversations led me to discard some of the misperceptions I had held and to rethink the parents' life decisions and practices from their point of view.

The second phase of my fieldwork, in the spring of 2003, can be characterised as the process through which I gathered a much broader knowledge of other parents' groups and their activities, and extended the scope of the research participants beyond the APCCP group. As the fieldwork progressed, I came to realise that there had been a rapid growth in the number of active parents' groups in recent

years and that they were conducting various forms of group action to achieve the rights of disabled children. This realisation came via various channels, sometimes by chance. For instance, I met and had the opportunity to have personal talks with some parents about their groups when I went to the parents' seminars to discuss specific issues, such as inclusive education. Sometimes, in the course of talking about my study with disabled friends who were working in disability organisations, they told me about the parents' groups they were working with and introduced me to the leaders. Because one of the main research inquiries was about parents' group politics regarding disability, my attendance in order to learn about other active parents' groups influenced the subsequent fieldwork process. In particular, those groups that were led by young parents and involved in direct political action attracted special attention. Besides working at the APCCP, I found myself driven to contact other parents' groups and became eager to participate in the various forms of parents' gatherings that they organised, as this would provide a rich knowledge of parental group activities. In this process, I met some leading activists who had long been involved in the parents' disability movement. The stories they told in the course of our conversations or interviews greatly helped me to grasp the central features of the parents' groups and understand their activities within a wider social context.

Another main activity in the second phase was to conduct the first set of interviews. Seven parents took part: four parents in the APCCP and three leading members of other parents' groups. I completed the interview write-up (with an initial analysis of the interview narratives and exploration of the theoretical themes) after the first set of interviewees had been completed. This activity turned out to be worthwhile in designing the sample selection for the second round of interviews and

developing new or extended interview questions.

In the final phase of my fieldwork, from May to August 2004, I focused on conducting the second round of interviews. The interviewees were recruited from nine other parents' groups besides the APCCP. After an initial contact with or visit to those groups, I completed the interviews with the members of the APCCP before I finished working at the organisation. With regard to the interviews with parents from other groups, my first contact was usually with a person identified as a leading member of that group. At the end of each interview, I asked him or her to recommend any parents whom he or she thought might be receptive to involvement in my research. Each leading member gave a list of names with brief information about the potential interviewees or arranged the interviews for me. The interviews with the parents in some groups necessitated travelling to other cities and staying there for three or four days. In those cases, I tried to schedule all of the interviews in the same week when they were conducting certain group events as a way of also getting a better understanding of their group.

Research methods

In-depth interviews

I interviewed a total of twenty-nine parents, who were involved in parents' self-help or advocacy groups. I was able to contact each one by telephone at least once prior to the interviews. During the initial telephone conversations, when I invited the parents to participate in the research, I briefly described its aims and objectives. I also sent an introductory e-mail to inform them about my personal background and give initial

information about the purpose of the study and what would be required of them. In this initial contact, some parents gave me the address of their internet homepage, which contained pictures of their family and stories about rearing a disabled child (such as their school life) or sent me via e-mail an autobiographical essay. This enabled me to get some knowledge about the participants prior to the interview and prepare more specific interview questions.

I let the parents choose the site of the interviews – ‘anywhere you feel most comfortable’. The selection of the sites varied. Some parents invited me into their homes and we would have dinner together. I met three mothers in parks because they wanted to break away from the confines of being indoors. Four mothers preferred to meet at their child’s school or at the place where their child received an educational programme, because such an arrangement was more convenient for them. Most interviews ranged between two and three hours in length. In some cases, the interview took much longer because it needed to be temporarily halted in order to care for the child or conduct other activities (for instance, going to school to pick up the child).

At the start of the interviews, I reiterated what I wanted to accomplish in this research. I told each parent why I wanted to listen to stories of parenting a disabled child. Usually, I positioned myself as a ‘learner’ who wanted to understand their lives and obtain an in-depth knowledge about the problems they were experiencing. I also informed the parents that pseudonyms would be used instead of their real names and that other identifying information would be removed to ensure that their anonymity and confidentiality would be respected. I assured the parents of their right to withdraw from the research project if and when they found that the research

procedures put their emotional well-being at risk.

I conducted in-depth, semi-structured interviews. In doing so, I tried to diminish my authority to control the interview situation so that the parents would participate in the interview more actively and so that their stories would unfold in the way they wanted. Although the interview was guided by a set of predetermined questions, these questions were used as a 'conversational agenda' to set the stage for generating and activating the respondents' narratives (Holstein and Gubrium 1995). Guided questions were used to help the parents to begin to tell their stories of their personal experiences, or critical life events, or to give accounts of their world, rather than as tools to extract definite answers. The degree to which the guided questions were used varied from one interview to another and, as the research advanced, these questions were modified and diversified.

During the interviews, I tried to construct a situation that resembled those in which people naturally talk to each other about important things. The interview was conducted in the style of an everyday conversation, rather than a 'formal question and answer format' because the respondents would then feel more comfortable about talking openly about themselves and expressing their true feelings and views (Mason 2002). In the course of the interviews, encouraging comments, shared sentiments, and topics of mutual interest were interjected whenever possible in order to prompt the respondents' active participation. I also sensed that the conversational and dynamic style of interviewing helped to turn the interviews into occasions for story telling (Denzin 1989). In fact, as the interviews progressed, the parents responded with stories, selecting particular experiences, and often took control because these were stories that they wanted to tell. When this shift occurred and the respondents

seemed engrossed in what they were saying, I tried hard not to interrupt. Only when the interviewee talked at length about extremely specific issues, such as the effect of a therapeutic programme on their child, did I change the subject by gently interjecting other questions.

Participant observation and other activities

Participant observation was another main research method for collecting data, particularly in relation to the parents' group activities. My participant observation was undertaken through the whole period of the fieldwork and in various settings. The APCCP was used as the primary base for this aspect of the data collection. I attended the monthly meetings of the board members, as well as a number of parents' meetings and seminars. I also joined in the organisation of various group events for disabled children and their families. As my friendships with the members developed, I was often invited into the parents' informal gatherings, such as dinner parties and picnics. These experiences of participation greatly helped me to become immersed in their community and gain a deeper understanding of the lives of these parents with disabled children.

My participant observation was conducted with the theoretical expectation that the parents' self-help groups can act as an alternative space in which certain counter-discourses against dominant disabling values are cultivated and disseminated. This expectation was confirmed in many ways. By observing their interactive communication, either during face-to-face meetings or virtual relationships, I was able to discover how they actively created their own meanings of living with disabled children in a collective way, and how they defined disability problems from their

own perspectives. I was also able to see how various forms of supportive and advocacy activities – which might go unnoticed by outsiders – were actively conducted in their daily lives and how many parents gained a sense of empowerment from these interactions. The lengthy period of participant observation provided me with the crucial knowledge and insights to understand how parents in the groups developed a collective identity and a community culture.

As discussed in the section on the ‘research process’, I also tried to participate actively in the parents’ forums and seminars that other groups organised. These extended activities provided me with the opportunity to listen to vivid stories of discrimination against disabled children that were seldom reported in the formal documents. I recorded such stories in field notes during or after each session and used them as an additional data source.

While I was clear at the outset that my motive for participating in various forms of parents’ group activities was research-related, my experience of participation soon took on a life of its own. Through continually working with the parents in those groups, I found myself moving towards multiple roles – academic researcher, advocate for disabled children’s rights and a member of the vanguard of the parents’ disability movement. My participation in the parents’ group actions also became a space in which my political convictions found a channel for expression. In retrospect, I became far more involved in the parents’ activism (including direct political actions) than I had anticipated.

Throughout the period of the fieldwork, in addition to participant observation, I collected the relevant documents and written materials. These can be grouped into: (a) documents published by the parents’ groups; (b) writings by

parents; and (c) e-mailing lists. Firstly, newspapers, seminar materials and other written documents provided an important data source which allowed the identification of the issues, values and activities that the parents in the groups had developed over time. Secondly, the parents' autobiographical writings were considered valuable material in getting deeper understandings about what meanings that they gave to living with a disabled child. The final resource I collected was e-mailing lists. All of the parents' groups had an on-line homepage and operated mailing lists to exchange information or discuss certain issues. Checking the lists was particularly useful in the early stage of my fieldwork to discover what kinds of common barriers they encountered; it also provided many insights into how they interacted and forged networks of mutual help in their day-to-day lives. Taken together, the materials obtained were used to validate or supplement the data collected from the interviews and participant observation.

Description of the research participants and parents' groups

The parents who participated in the research were recruited through parents' self-help or advocacy groups. I contacted twelve parents' groups and was able to visit those groups at least once or to have an initial conversation with their leading members via e-mail. Two parents' groups I contacted were excluded from the process of recruiting interviewees because they did not engage in specific activities or consisted of a very small number of parents.

The parents' groups from which the participants were drawn displayed some common characteristics. They had been formed very recently and were led mainly by

young parents whose children were enrolled in schools. The groups were controlled and operated by the parents themselves even though some groups also employed staff. Undertaking leading roles in the groups was basically voluntary and approved by all of the members. However, the forms of the groups and the main activities in which they engaged varied substantially. Two groups were organised on the basis of a single category of impairment. Three were focused upon special issues, such as the right of to inclusive education, and many others had been formed on the basis of regional circumstances. The membership of each group ranged in number from about 150 to 300. Some groups were loosely organised and had no office from which to conduct their activities; however, this does not mean that these were less important than the other groups.

Individual interviews were arranged with eight parents in the APCCP, fourteen in the other parents' groups located in the city of Seoul and in Kyeong-Gi Province (containing almost one third of the total population of Korea), and seven in three other cities. All but two of the parents were interviewed once. The two exceptions were interviewed twice because they had a great of information on the parents' disability movement. Exchanging e-mail with some parents after the interviews was necessary because, while listening to the recorded interviews, I realised that I had forgotten to ask some important questions, and that their responses were incomplete owing to interruptions during the interview. Seven parents supplemented their earlier comments or told additional stories in two or three e-mails.

Table 1 presents the information about the interviewees. In a broad sense, all of the parents belonged to the Korean middle or upper-middle class in terms of their income and job status. The interviewees ranged in age from 38 to 61; however, most

of them were in their forties. All of the families were two-parent households. Nine fathers and twenty mothers were interviewed. The children's impairments, as identified by the parents, included cerebral palsy, intellectual disability, autism, Down's syndrome and behavioural problems. Some of the children had multiple impairments. In all but one case, the impairment reported was congenital.

Table 1 Description of the research participants

	Name	Gender	Age	Child (age)	Impairment	Status in organisation
1	Dong-min Jin-seok Jae-ok Jin-ho Woo-seok Da-hee Ji-soo Yang-hee	Father Father Mother Father Father Mother Mother Mother	40s 30s 50s 30s 40s 40s 40s 40s	Son (11) Son (8) Son (24) Son (12) Son (10) Son (11) Son (11) Son (9)	C.P. C.P. C.P. / I.D C.P C.P C.P C.P / S.I C.P	Leader Member Member Member Former leader Leading member Head in CTH Member
2	Yun-seo Jeong-hee Ji-weon Eun-kyeong	Mother Mother Mother Mother	40s 40s 30s 30s	Son (12) Son (9): Son (7) Son (9)	B.D (AT) I.D / B.D I.D / B.D I.D / B.D	Leader Leading member Member Member
3	Da-sol Soo-hyeon	Mother Mother	40s 40s	Son (11) Son (10)	B.D I.D (AT)	Leader Leading member
4	Min-woo Ji-min	Father Mother	40s 40s	Son (16) Son (13)	AT I.D / B.D	Leader Leading member
5	Tae-hee Jeong-eun Moo-seong	Mother Mother Father	40s 50s 40s	Son (11) Son (15) Daughter (10)	B.D (AT) B.D (AT) I.D / B.D	Leader Leading member Leading member
6	Mi-seon Mi-jeong Jae-hee	Mother Mother Mother	50s 40s 40s	Son (22) Daughter (16) Son (20)	C.P C.P C.P	Leader Leading member Member
7	Yun-ji Min-joo	Mother Mother	50s 40s	Son (17) Son (15)	D.S. I.D / B.D	Leading member Leading member

8	Dae-whan	Father	60s	Son (31)	I.D	Leader
	Je-ook	Father	40s	Daughter (14)	I.D	Member
9	Seo-hee	Mother	50s	Son (16)	D.S	Leading member
10	Dong-keon	Father	40s	Son (9)	B.D (AT)	Leader
	Ka-yeon	Mother	40s	Son (11)	B.D	Member

[Notes]

Parents' group- 1: APCCP, 2: SAPHRDP, 3: KPAMS, 4: SAPDC, 5: APERDP, 6: TAPDC, 7: CAPDC, 8: APDCS, 9: APCD, 10: KAPDC

Impairment- C.P: Cerebral Palsy, I.D: Intellectual Disability, B.D: Behavioural Disability, D.S: Down's syndrome, S.I: Sight Impairment, AT: Autism

Data analysis and interpretation

It is difficult to pinpoint exactly where data collection stops and data analysis begins, but, typically, in qualitative research, these two activities feed into one another (Glaser and Strauss 1967). As mentioned above, I began the initial analysis of the data in the course of the fieldwork, usually when writing the field notes. However, the systematic analysis began from the time when I transcribed the tape-recorded interviews after leaving the research field. All of the interviews were firstly transcribed in Korean, my native language, in order to make it easier for me to scrutinise the converted text and also capture the meanings of the narratives.

Transcribing verbatim in this way entailed close, repeated listening to the narratives. While transcribing, I inserted my own observations and analytical comments in brackets. These were taken from the memos in the field notes, which recorded the process of the interviews, the nature of the interactions and the contents of our chats during the time when the interview was halted (e.g. when having dinner together). Transcribing the taped interviews verbatim also involved a process of

recollecting the ideas or impressions I obtained during the field research and re-experiencing the social encounters. On these bases, the meaning making process was activated. A host of analytic comments emerged: some were taken from the field notes and others emerged spontaneously. I inserted these analytical comments at the end of each segment of the narrative. This process included making sense of important, striking aspects of the data and some initial theoretical insights that I was beginning to formulate. I viewed these reflective activities in the process of transcribing the interviews as the initial phase of the systematic data analysis.

Many analyses of the qualitative data begin with the identification of the key themes and patterns, and this often depends upon the process of coding the data (Coffey and Atkinson 1996). Seidel and Kelle (1995) argue that coding can be used as a 'heuristic device' for identifying meaningful data, setting the stage for the interpretation, and opening up more diverse analytical possibilities. They propose that coding is most often associated with undertaking three kinds of operation: (a) noticing relevant phenomena; (b) sorting out examples of those phenomena; and (c) analysing those phenomena in order to find commonalities, differences, patterns and structures (Seidel and Kelle 1995: 55-6). After completing all of the transcriptions, I began the process of coding. First of all, this involved classifying and organising the data into a manageable form. Miles and Huberman (1994) propose that an unwieldy body of textual data – whether interview transcripts, field notes or other documents – can be condensed into equivalence classes and categories, based on the conceptual schema. While I read repeatedly all of the interview transcripts, I identified 'units of meaning' (thus 'analysable units') in the narratives and began assigning categories into them (Coffey and Atkinson 1996). The categories created in the first round of

the coding, reflecting substantial research questions, took the form of broad-based or generic concepts such as family problems, relationships with professionals, special parental roles, the self-definition of disability problems, group actions for social change, and so on. In this process, the narratives were segmented and chunks of varying size (words, phrases, sentences or whole paragraphs) were singled out from the transcripts. Codes were attached to each of the segmented narratives and those fragments were grouped together under identified or constructed categories. The field notes and collected texts, such as the parents' writings, were also sorted in the same way. As part of an analytical process, this code-and-retrieve procedure enabled me rigorously to review what was emerging from the data, and to generate analytical ideas and concepts with regard to the emerging themes throughout the data texts.

The second stage of the coding was to interpret the narratives. A constant comparison (Glaser and Strauss 1967) was also included in this process. Clustered segments of narratives were compared and contrasted. This often led to the development of a number of sub-themes or the modification of the primarily applied categories; consequently, some segments of the data were re-sorted and reordered. I often revisited the literature that had grounded the research in order to connect the narratives to the relevant theoretical frameworks. However, as the process of interpretation continued, I realised that I sometimes fitted segmented narratives to the frameworks by lifting them from their contexts; this often resulted in over-generalisation or neglecting adverse cases that needed to be explained. This required me to revisit the original manuscripts and re-interpret them.

Whilst meaningful themes and interpretations were immediately apparent, the complex dimensions of the parental experiences and practices frequently made it

difficult to decide what should be highlighted (and omitted) and in what terms I should frame the emerging themes. In this process, I often returned to the original research questions and asked myself whether the themes were adequate to answer those questions. Sometimes, after a long drawn-out process, I re-assembled the themes into four areas: (a) the early period of transition to disability-parenthood; (b) everyday family lives; (c) experiences of schooling; and (d) group working. The first three chapters of the analysis of these data (Chapter 4, 5 and 6) provide me with the opportunity to explore in detail the participants' personal experiences of disablement and 'disability work' (including the extended parental roles). Regarding the experience of group working, I framed the themes and sub-themes according to the main research questions: how they did come to be engaged in group working? (Chapter 7); and what did they develop through working together? (Chapter 8)

CONCLUSION

This chapter presented the social context in which the research was conducted and discussed the significance of the research in relation to the changing social and political circumstances. It has been a long-established tradition in Korea to regard the 'problem' of disability as a personal and family issue and, consequently, the welfare of the disabled child has been identified as essentially a family responsibility. This research was primarily initiated to enhance the social recognition of the problems of disabled children and their families.

In this chapter, I explained the research process. It became clear that

developing research inquiries and choosing one particular methodology over others was far from a neutral act. The social constructivist paradigmatic understandings of the reality of disability and the emancipatory notion of disability served as the ontological and epistemological foundation for designing the research. I explained how my own subjectivity, including my previous experience and values, was interwoven with the research from the outset. In conducting this research, I tried to eradicate the traditional researcher-researched relationship, and to place the participants at the centre of the research. Developing reciprocity, securing workable dialogue, and promoting self-reflexivity were all important issues that I had to consider in the research process. The research was conducted by employing multiple research methods in order to obtain a deep understanding of the world of the parents and information on their group activities.

The following three chapters present the parents' accounts of their experiences of disablement and their practices as parents of disabled children. In the next chapter, I will explore their early parental experiences, and will also investigate how those experiences have intersected with the wider social and cultural circumstances.

CHAPTER FOUR

BECOMING THE PARENT OF A DISABLED CHILD

INTRODUCTION

In this chapter, the parents who participated in the study recall their early experiences of coming to terms with living with their disabled child and provide accounts of the circumstances in which they underwent those experiences. For none of the parents were these recent events, so their stories of their early experiences are undoubtedly coloured by the passage of time and subsequent life experiences. However, these intervening years enabled them clearly to articulate their situations and the barriers that they had experienced.

EMBEDDED REACTIONS

The impact of the diagnosis of the impairment often comes as a shock to the parents and they are likely to experience a mixture of emotions, ranging from disappointment to anger, denial and grief (Seligman 1991). In order to understand the parents' reactions to having a disabled child, we have to take society into account. As

Ferguson (2001: 374-5) writes:

[A] family's reactions to having a child with a disability are inescapably embedded within a socio-historical context [...] how a family interprets the meaning of disability cannot help but reflect to some degree the larger context of social attitudes and historical realities within which that interpretation emerges.

The majority of the parents who participated in the study had never imagined that they might have a disabled child. The narrative below is similar to most parents' recollections of their initial reaction to the news of their child's impairment:

When my husband told me that our child had been born with Down's syndrome, everything went dark as pitch and I couldn't stop crying...I had never thought, even in dreams, I would ever give birth to such a child.

[Seo-hee]

Having a 'normal' child was usually perceived as the natural process of their transition to parenthood and thus was taken for granted. When the parents expressed concerns about the health of their unborn child, these concerns were usually discounted by friends, relatives, and others. Even when the parents, particularly the mothers, had been worried about the possibility that their child might be born with a problem, any mention of 'birth defects' was forbidden:

[Da-hee] I got pregnant so late compared to other mothers. So I was very worried about my baby's health...because I'd heard somewhere that, in cases like mine, there's a possibility of having a *gi-hyeong-a* [deformed baby].

[I] Did you discuss this with anyone?

[Da-hee] I tried to discuss it with older sister and my mother...but they

interrupted me and told me not to say any more.

[I] Why?

[Da-hee] Because it's not good for the baby...they said... 'Don't think about bad things. Pregnant mothers shouldn't say such words. Words are the seeds of misfortune'

Within the Korean lay culture of *tae-kyeo* [which emphasises the pregnant woman's fetal education], prospective parents are very strongly encouraged to think about only good, beautiful and happy things (Kim, 1996). In this process, as the mother's experience shows, it is strictly forbidden for them to express doubts about the unborn child's 'normality'. It is also a cultural taboo even to mention a possible impairment or birth defect during pregnancy. What should be noted here is that this lay cultural practice resonates with, and often facilitates, the social marginalisation associated with parenting a disabled child in South Korea. Under the conditions in which the idealised notions of a 'healthy and perfect' child are naturalised, the birth of a disabled child is identified as the most tragic and dreadful life event (Greenspan 1998). In addition, the possibility of having a disabled child is usually consigned to the domain of the 'unmentionable' and, thus, all discussion is 'silenced' in the transition to parenthood (Gregory 1991).

It has long been argued that the segregation and exclusion of disabled people from mainstream Korean society has contributed to their invisibility in everyday life (Jeong 2001). In such a deeply segregated society, the parents are likely to encounter their disabled child with little or no prior personal experience of interactions with disabled people and their families:

As I bring up my child, the most surprising thing to me is that there are so many disabled children like my child...and there are so many with an even

more severe impairment...But, surprisingly, I never saw such children when I was growing up...There must have been children like that in the past as well...I was really curious about why I hadn't seen them.

[Ji-soo]

Like Ji-soo, most of the parents reported that they had grown up with little contact with disabled people. It seems that the social invisibility of disabled people and their families was a main factor in determining the parents' holding of a very narrow, distorted view of disabled families, and hence they regarded having a disabled child as an 'abnormal' phenomenon. In this context, it is unsurprising that the parents in this study lacked factual knowledge about various impairments and were poorly prepared for the birth of their child. In many cases, the parents were not even aware of the existence of their child's impairment prior to the baby's birth:

- Before a doctor mentioned it, I'd never heard of autism. [Min-woo]
- I'd heard of it [cerebral palsy] somewhere, but I was totally ignorant about it... I thought it was a very rare illness. [Jin-ho]
- I heard about developmental disability in a hospital for the first time. I didn't know there was a such disability. [Min-joo]

Most of the parents pointed out that, before having a disabled child, they had held values about disability similar to those that they now found problematic. Interestingly, the belief that the birth of a disabled child is due to the 'pathology' of the family was shared by a number of parents. It was a result of their socialisation, particularly of the dominant cultural perceptions of families with a disabled child:

Whenever a family with a disabled child appears on television, they're always poor and miserable, deficient in some way. The parents are divorced...the mother is raising her disabled child alone...the house is messy, full of rubbish...as if a disabled child is only born in such households...Before I had a disabled child, I thought too...a disabled child always comes from a such horrible families like those.

[Dong-min]

Such perceptions are still prevalent among Korean people and even among the educated. Eun-kyeong's story illustrates this well:

One thing really shocked me...It happened that one of my son's classmates hit him. So I visited the school and saw the principal...I was crying while I talked to him...the principal said 'So what do you want?' and I said...'Please report it to the LEA [Local Educational Authority]...because there are other disabled children in this region, and ask them to do a survey'...His response came as such a shock...You know what he said?...He said that my son was the only disabled child in this area because the people here are at least middle class. That's how the head teacher replied to my question...

[Eun-kyeong]

DISCOVERING THE CHILD'S IMPAIRMENT

It might be stated that the moment when the parents learn the news of their child's impairment is generally dependent upon the nature of the impairment. If their child is born with an obvious impairment, the parents usually know straight away that there is something wrong. On the other hand, some impairments, such as autistic syndrome, may not be readily apparent in the child's early developmental stage, and so the parents may not be aware of their child's condition until much later (Seligman and Darling 1997). However, the nature of the impairment is not the sole factor determining the process of the parents' discovery of their child's impairment. The

extent of the public awareness of disabled children, the parents' cultural or lay knowledge about impairment, the socially arranged forms of diagnostic systems and the medical professionals' attitudes all influence the process of the parents' discovery of their child's impairment and related experiences (Beresford et al. 1996; Seligman and Darling 1997; Sloper et al. 1991). Among the parents who took part in the study, in only four cases had their child been born with obvious signs of an impairment. They had noticed the child's 'strangeness' through their daily interactions with him or her. As illustrated below, when the signs of an impairment were not readily apparent in the early stage, the parents usually considered their child's difference as a 'normal' child's developmental variation and identified it as the sign of a 'slow developer':

I'd always felt that he was somehow strange. But the people around me all said, 'A child may be a little behind. Boys may be late in walking' so I just thought that was the explanation. But he didn't manage to walk until a good while after his first birthday...As time went by, I grew more and more anxious...and I began to suspect that there was really something wrong. When he was about two, I began to go here and there to try to find out about his condition.

[Jin-ho]

As their child's difference persisted or developed, the parents reached the point where they could no longer avoid their suspicion that something might be seriously wrong. Once they reached this point, the parents took the next step sooner or later; namely, seeking a diagnosis of their child's condition. However, seeking a diagnosis did not necessarily mean receiving one. The problem of a delayed diagnosis was raised by most of the parents in the present study. Some reported that the medical professionals knew but avoided giving a frank explanation of their

child's impairment:

The first doctor I met didn't say what was wrong with my child. He just said 'Wait and see how he develops'...But I felt that that doctor seemed to have some idea about what the problem was. A few days later, my friend who worked at the hospital introduced me to another doctor. After he examined my son, the doctor gave a diagnosis of cerebral palsy.

[Jin-seok]

Issues around diagnosis came up repeatedly as the parents described their early lives with their disabled children. A diagnosis, the identification of the condition of the child's impairment by recognising signs or symptoms, may seem like a straightforward scientific procedure; however, as Clavering et al. (2007) underscore, a diagnosis does not occur in a vacuum: a range of social and cultural factors influence the ways in which the parents experience the diagnostic process. For example, the mothers' concerns over their children's difference were discounted very easily by the medical professionals on the basis of the cultural assumption about protective mothers who were 'neurotic' about their children (Landsman 1998), as the narrative illustrates:

My child showed symptoms of infantile epilepsy in the early years. He'd stop abruptly in the middle of his action for about a second and the pupils of his eyes would drop. At first, it happened once every few weeks...but, as he grew up, it happened more and more. So I went to a doctor and told him about it, but he didn't take it seriously; he just said 'It's happening because he's still an infant'...as if I were being over sensitive...but I noticed it several times...One doctor even scolded me; he asked 'Do you want to make your child into an abnormal?'...I went to another children's clinic, and then another...when I consulted the fourth doctor, I picked the right moment, because my child showed the symptom.

[Eun-kyeong]

When the parents were told that something was wrong with their child but a complete diagnosis was delayed, many had to suffer a prolonged period of uncertainty and anxiety. While the label at the time of identification and diagnosis was seldom considered by the parents to be a life-long sentence, they often felt that, without the label, they could not move forward. This led the parents to shop around for medical advice in order to obtain a precise identification of their child's condition:

When my child was two, I went to a doctor to inquire about my child's problem for the first time...but none of the doctors in this city could tell me anything about my child's impairment...So I thought it was a kind of rare illness. For about a year, I went to many hospitals...I went to see this doctor, that doctor and another doctor...I spent a lot of money too, not to mention time.

[Yun-ji]

Such a 'diagnostic limbo' between suspicion and confirmation can be extremely stressful (Edelson 2000). Nearly all of the parents in the study argued that it would have been better to be aware of their child's condition and receive diagnostic information as early as possible. The delay in informing them of the child's condition and providing diagnostic confirmation – driven by the doctors' 'wait-and-see' attitudes – always increased rather than alleviated the parents' anxiety and uncertainty. As Ji-weon's comments suggest, the parents generally looked for honest information and openness from the medical professionals, even though it might not be possible to give a definitive identification of their child's condition until a later stage of development:

I met a really good doctor. He was competent and very caring about my

child...he treated my son just like any other child...He gave us more time than we originally arranged...and encouraged me a lot by saying that 'your son shows many symptoms of developmental disability, but at this moment we can't predict his development precisely. A lot can change as he grows up'. From the beginning, the doctor explained about the behavioural problems that might occur as my child grew up and suggested that I should apply for early education. He wrote a detailed reference letter for me. I think I was luckier than other parents.

[Ji-weon]

DISCLOSURE AND DISABLING PROFESSIONALS

Whether it takes place at birth or later, the disclosure of their child's impairment is a key moment in the early lives of the parents of disabled children (Darling and Darling 1982). Besides the parents' understandable feeling of traumatic crisis or initial shock driven by the news of their child's impairment, it should also be recognised that the nature of the information or the message that the parents receive have repercussions for both the parents' reactions to the child and their immediate course of action (Read and Clements 2001). It has been widely reported that there continue to be problems with the manner in which the information is conveyed and with the information itself (Cunningham 1994; Sloper and Turner 1992, 1993). The accounts of the parents in this study confirm this, and further reveal that the medical professionals often act as a conduit for disabling values.

A substantial number of parents in the present study suffered traumatic experiences in the diagnostic setting owing to the medical professionals' failure to value their child:

I was so hurt by what the doctor said...He was so rude and spoke thoughtlessly...when he made the diagnosis, he explained my baby's condition like this... 'Give him a spoon and he won't need friends. He'll play with the spoon all day'...I'm his mother and he's my son, just like any other mother and child...doctors shouldn't talk like that.

[Yun-seo]

Like the parents of non-disabled children, the parents of a disabled child want him or her to be taken seriously and treated with respect. As Yun-seo's experience demonstrates, the medical professionals did not appreciate the child's 'unique personhood', instead condemning the child to a bleak future in terms of his or her development (Featherstone 1981). In addition, the medical professionals were usually more negative about the disabled child's quality of life than the parents had expected. Seo-hee, who has a son with Down's syndrome, described the medical professional's reaction:

The doctor asked me my age, and then he said 'Have a healthy baby while you're young. Don't cling to this baby too much. He'll never be a 'normal' child. It's better not to hope for much from him'...How could he say so easily that I should give up on the child? Why didn't he encourage me to bring him up well?...After meeting the doctor, I suddenly felt I was alone...it was like there was no one on my side.

[Seo-hee]

Some of the parents were traumatised by a medical professional's 'blaming-victim attitudes' (Hillyer 1993). In particular, psychoanalytically oriented physicians often tended to attribute the cause of a child's disability (its etiology) to parental failure, especially a lack of maternal care or affection. This placed an additional burden on the parents who were already stressed by the news of the child's disability,

and often exacerbated their feelings of guilt:

When I heard the diagnosis of my child's problem, the doctor told me 'it's a type of affective disability among developmental disabilities'...He explained it like this: 'The mother's lack of affection for the child in the period of infancy can cause it'...and said, 'Pay more attention to the child and spend lots of time with him'...For a good while, I was trapped in guilt feelings towards my baby because of the doctor...I started work again around ten months after having my baby. So I left him with his own grandmother who lived nearby...Because of what the doctor told me, at the beginning, I believed it [the child's impairment] was my fault...but, after a good while, I realised that the doctor always said that the children whose mothers worked had an 'affective disability'.

[Jeong-hee]

The medical professional's relationship with the parents in connection to the child's impairment was based on a 'medico-functional perspective'. In the diagnostic setting, the medical professionals generally identify a child with an impairment in terms of having a physiological deficiency and functional limitation (Darling and Darling 1982). The medico-functional perspective is not entirely wrong. The parents have to learn the nature of their child's impairment and its bodily effects in order to provide relevant treatment and develop competent care practices. However, it is also important to note that the professional's attitudes towards and ways of dealing with disabled children often reflect and reproduce disabling ideologies (Meddleton 1999; Oliver and Sapey 1999). The medical professionals often served as agents reproducing and imposing disabling ideologies in their interaction with the parents:

When I went to the hospital to be told the diagnostic test results, the doctor showed me the sheet, and explained, 'Your child has one more chromosome than a normal child'...I asked him 'What does that mean? What's the problem with my baby?'...The doctor said to me 'In a nutshell, she's a *'babo* [idiot]' So I asked him, 'Will she be able to go to school?' He said 'She'll not

be able to go to 'normal' school; She'll be lucky if she learns to cook noodles by herself'...When he said that, my mind went blank. I couldn't think of anything to say. I just cried and cried...I can't remember how I got home.

(The mother of a daughter with DS)

[Source: e-mail on 22-9-2003, <http://www.down.or.kr/boardRead.html/>]

In the disclosure of the diagnosis, as the narrative above illustrates, the disabled child was often defined as 'incapable of being normal'. It does not simply inform the child's impairment in terms of a divergence from the milestone of a 'normal' child's development. The message conveyed to the parent was that the life of a disabled child was meaningless and hopeless. The medical professional equates a set of physiological characteristics or functional limitations to a 'fixed and devastating developmental trajectory' (Larson 1998). In this case, the medical professionals nourished fears and prejudices about disabled people in their interaction with parents.

HOW MUCH IS LEARNT?

When the parents recalled their experiences in the immediate period following the diagnosis, they underlined the fact that their initial fear and frustration were not simply driven by the fact that their child had an impairment. Although a diagnosis had been obtained, many of the parents were typically still left feeling uncertain about what the diagnosis meant. When the implications of the child's impairment were not precisely stated or were discussed in vague terms, some of the parents remained confused and anxious:

He just mentioned that my baby had the symptoms of severe autism...nothing more...he didn't try to explain it in detail...you know...it was the first time I'd had heard the word. How could I know anything about it?...I was so afraid because I didn't know what it was, what my child would be like...Fear comes from ignorance, doesn't it?...

[Jeong-eun]

Many of the parents reported that they had not been given a sufficient explanation by the doctors in the first diagnostic setting. Indeed, a significant number of parents perceived their child's impairment as a kind of 'rare illness' or 'disease'. Some of the parents learned about their child's impairment and its longer-term implications through alternative sources that they personally sought out, and sometimes by chance:

For a long time I hadn't known very much about autism...because the doctor didn't explain what he would be like...I had thought for a long time it was a kind of rare illness...Nowadays there are so many books about autism, but at that time, as far as I know, only two books had been published...My wife got hold of them...After reading them, I realised that autism is not curable, and you have no option but to live with it.

[Min-woo]

In contrast, the parents who met medical professionals who showed emotionally and practically supportive attitudes evaluated their assistance as most helpful resource for their early coping with their child's needs and preparation for their new life:

The doctor I met was a really good person. Finding her was such a piece of luck for my child and me...She had a niece with severe CP (Cerebral Palsy)...The treatment she gave my child was the same as she gave her niece, and she gave me lots of tips I could use at home. I learned so many things from her...It was more than any of the other doctors did for my child. The

relationship with her was as if she was part of our family. She treated my baby like her own niece.

[Yang-hee]

BARRIERS TO ACCESSING INFORMATION

As widely acknowledged, the provision of information and advice is central to the parents' managing and coping with the difficulties they encounter in the early years (Read and Clements 2001; Sloper and Turner 1992, 1993). The need for information about valuable services is not instrumental in terms of the child's improvement but also important in developing the parents' skills and knowledge. As Darling and Darling pointed out:

Once an accurate diagnosis and prognosis have been established, parents generally want to know what can be done to help their child. Most parents have an *action orientation*: they feel a strong need to *do something* to maintain their self-esteem as parents.

(1982: 124 emphasis in original)

If sufficient information is unavailable, they are likely to feel that they are powerless and lack control. This, in itself, can lead to anxiety and a crisis of parenthood (Beresford et al. 1996). It has been suggested that around the time of the identification of their child's impairment, it is particularly important for the parents to receive information and resourceful, realistic advice for both themselves and their children (Robinson 2001).

Nearly all the parents in the present study reported that one of the most common experiences in the early years was difficulties in accessing information and

knowledge about services, either directly related to their child's needs or to guide the parents. One mother described her experience as follows:

I didn't hear about any information from the doctors...I didn't know where I could get such information...where to go, who I would have to consult about my child's problem, what kinds of treatment would be necessary...So, at the beginning, I was at a loss what to do...so frustrated...If there had been some kind of manual, it wouldn't have been so difficult.

[Ji-min]

Many of the parents had to depend upon their own personal, informal resources and make extraordinary efforts to obtain such crucial information. Unsurprisingly, this process often depleted their energy and led to stress. Eun-kyeong commented that:

It was entirely the mother's responsibility...I went here and there all by myself to gather some information...it was like looking for an oasis in a desert...If there were a proper information centre, I could find out what kinds of programmes were available, how to use them, where to go...it shouldn't have been that hard and stressful...I was totally bunt out doing that.

[Eun-kyeong]

Some parents got to acknowledge about the basic services for their child's special needs by chance, as the following narrative illustrates:

For about eight months [after receiving the diagnosis], I didn't know there was an early education class...I didn't even know the fact that my child needed such treatment...A mother of a friend of my [non-disabled] first son lived in the apartment in front of the SWC [Social Welfare Centre]. The mother told me about it and suggested I go there...that's how I got to know about it.

[Tae-hee]

THE RELATIVES' REACTIONS

The attitudes of relatives are particularly significant in the very early stages. Unsurprisingly, the extended family members' emotional support and full acceptance of their disabled child in spite of his/her difference is a most powerful resource for the parents in the early period (Hornby and Ashworth 1994). Jeo-ok commented:

I received emotional support from the family, in particular, my mother-in-law...In Korean society, mothers often blame their daughter-in-law when she gives birth to a disabled child, don't they?...But my mother-in-law accepted my son completely.

[Jeo-ok]

Unfortunately, some of the parents had to experience a very stressful period in dealing with negative reactions towards their disabled child. According to the parents, to think that the presence of a disabled child is a sign of a 'family blemish' remains prevalent in lay people's perceptions. Ji-weon was one of the mothers who experienced very negative reactions from her father-in-law:

His grandfather disliked the fact that he had been seen outside the house...He hid the fact that he had a disabled grandson...he kept it secret from his friends...His grandfather seemed to believe that other people would look down on him if they knew it.

[Ji-weon]

Jae-hee also talked about her sisters' reactions towards the child. Like others of the older generation, her sisters insisted that the disabled child should be sent to an institution, believing that he would bring her only continual pain and tragedy:

I was arguing with my oldest sister once...because she'd told me I had to send my baby away somewhere to an institution...so I challenged this. I said 'Put yourself in my place. Look at my side of it. What would you do if he were your son? Would you send him to such a place?'

[Jae-hee]

Another crucial feature of Korean Confucian culture was the mother-blaming attitudes that ascribe the birth of a disabled child to some defect in the mother's lineage. When the parents faced such negative reactions from other family members, they tried to resolve the situation but sometimes had to break off the relationship in order to protect both their child and themselves. Jin-ho was one of the parents who experienced a very stressful period while battling with this problem. He recounted that:

When my son was diagnosed, my mother and older sister called me and said, 'You must get a divorce'...they called my wife almost every day and put pressure on her to get a divorce...I argued with them several times...I couldn't endure it any more and said to them...'You are not my family any more. I am his father and she is my wife and his mother. Don't contact me any more'...After then, for about three years, I didn't meet my mother and sister...it was a terrible period of my life...

[Jin-ho]

In a culture that devalues disabled children it is too easy to adopt a negative view and dismiss children with impairments as worthless. The negative perception of the disabled child often leads to the deprivation of the disabled infant's right to receive relevant medical treatment in the name of the familial love of the sister:

In my case, it was a premature birth [...] my baby had been in an incubator

for a month...at that time, my cousin was an obstetrician at the hospital...ironically, she persuaded my mother to take the baby out of the hospital. She said, 'Do you want her to go on suffering? However well she brings him up, he'll never be normal'...So without informing to me, he was discharged from the hospital.

[Ji-soo]

PERCEIVED PARENTAL ROLES IN THE EARLY YEARS

The parents' reactions to their disabled children in the early years can be characterised as 'cling to treatment'. Despite variations in the children's impairment effects, nearly all of the parents had been overwhelmed by the anxiety that they had to change their child's condition with the hope of a cure or converting them into a 'normal' child as soon as possible. While seeking treatment had been conducted primarily within the regimes of modern (clinical) therapeutic practice, such as special stimulation programmes, many of the parents had also had recourse to Korean traditional medicine (e.g. Oriental herbal medicine, acupuncture). In some cases, this hunt for a treatment led the parents to explore pre-modern forms of ritual or folk healing practices:

Once we'd been told about these famous therapeutic clinics, we went to them to check if they were offering different ways of treatment...I don't know how effective and helpful it was to my child, but we took him to many famous Korean medical clinics and hospitals.

[Jin-seok]

My child received *Gi*-therapy...The therapist said 'If a mother gives her own *Gi* to the child it will be more effective', so I learned it and practised at home for a while.

[Jae-ok]

The fact that the parents' clung to therapy at any cost cannot be understood in isolation of the social context. Indeed, parental obsession about treatment was a reflection of the social uncertainty surrounding their child's future life. Da-hee commented that:

It is immensely difficult to live in a society as disabled person because society as whole ignores such people and does little to help them...this sometimes lead parents to cling to some hope of miracle...and cling to treatment, therapy at any cost....If our child's future life is secured, the mothers need not to hang on such things.

[Da-hee]

In a sense, these responses were understandable in view of their previous internalisation of negative values regarding impairment and the cultural pressure to be 'normal.' Despite variations in timing, the parents' obsession with finding a treatment that would 'cure' their child had gradually diminished and was replaced by a redefinition of their child and an acceptance of his or her limitations. The parents, as will be discussed in the next section, through their revaluation of the child's impairment, particularly their continual relationship building and inter-subjectivity, changed their early ideas about 'fixing' their child's impairment and came to see his or her limitations as a part of the child's unique personality.

CONCLUSION

This chapter has explored the parents' experiences of coming to terms with living with a disabled child. Generally, they had previously had little or no contact with

disabled people, and many of them had been socialised to hold negative perceptions of disabled people. Hence, this early period proved to be emotionally demanding for many parents. I also highlighted the fact that their feelings of disruption and experiences of anomie were shaped to a great extent by unsupportive social conditions. Many of the parents experienced negative reactions from disabling professionals and inadequate explanations of their child's condition. Most of the parents also experienced difficulties in finding out basic information about their child's needs and others discovered the key services by chance.

Usually, despite the variations in timing, the parents came to develop their own ways of living with the child and sought to create equilibrium in their lives. However, they persistently encountered practical problems in the daily management of their family lives. The next chapter will examine some of the central family issues that the parents commonly identified.

CHAPTER FIVE

FAMILY LIFE WITH A DISABLED CHILD

INTRODUCTION

This chapter presents the parents' accounts of their everyday family lives. Despite the variety of their experiences, they shared similar difficulties and dilemmas in practising good parenting. By drawing upon the parents' interpretations of their reality, this chapter investigates how an unsupportive social environment constrains their daily life management. It firstly explores the parent's struggles with material problems in order to meet the disabled child's special needs, and then discusses the issues associated with caring. Finally, it examines the main features of the mediating roles that the parents undertake, particularly in association with stigma management.

MATERIAL HARDSHIP

Caring for any child has an impact on a family's financial situation, relating to the costs associated with both outgoing and incoming resources. However, in families where a child has special practical needs, this impact may be accentuated. There is a

large body of research that suggests that families caring for a disabled child are at greater risk of financial disadvantage (Baldwin 1985; Baldwin and Carlisle 1994). As widely noted, the disabled child's needs for extra-care are likely to curtail the opportunities of the parent, especially the mother, to participate fully in the labour market (Dobson and Middleton 1998; Shearn and Todd 1997, 2000; Twigg and Atkin 1994). The effect of this diminution of the mother's ability to undertake paid work was also identified by many mothers in the study as a significant barrier to them securing their family's economic well-being:

The fact that I couldn't earn money any more was so threatening to our family...To pay back the money we'd borrowed to buy the apartment, both my husband and I had to work...now, we're living now in a rented flat again because there was no option but to sell the house...Rearing a child like my son is so expensive. The programmes my child uses cost too much...it seems we're getting poorer and poorer...income is low but expenditure for the child is always high.

[Eun-kyeong]

Eun-kyeong had worked for a small company for several years after she got married. Her family was typical in that the maintenance of the household economy was based on both parents being employed. At a time when additional resources were required to cover the increased spending related to her child, the loss of her earnings had a decisive impact on her family, increasing the likelihood of sliding into a lower economic status.

Even though some mothers tried to balance work and care in order to mitigate the financial burden, they encountered a range of obstacles:

Of course, I'd like to go back to my previous job...there are some mothers

who can continue to work because they get help from the family...but my relatives live far away...as you know, there was nowhere that would take care of my child all day...Hiring a helper isn't easy. It's hard to find a skilled and trustworthy person...even if I could, it would be very expensive. My child's case, we'd have to pay at least 1,200,000 won [£600] a month...so you can see it's not worth going to work.

[Da-sol]

It's very difficult for us to have a part-time job...I have to go to the school every day because we don't have a helper...when the school bell rings, my child is left alone in the playground...Other mothers are free when their child goes to school, but we aren't... on the contrary, we have more work to do all the time.

[Soo-hyeon]

The narratives above reveal the common difficulties that very many mothers encountered when they tried to participate in the labour market. When work and care could not be combined within their existing resources or informal networks, the mothers were forced to seek substitute care. However, as a number of Korean scholars have consistently remarked, public care providers, such as nursery schools frequently deny admission to disabled children and the availability of adequate care provision is highly restricted (Byeon et al. 2003; Kim 2003). Further, as Soo-hyeon's narrative indicates, an unsupportive school environment severely constrains many mothers from undertaking paid work. In order to continue in her previous job, Da-sol would have had no option but to hire a private helper. However, as she said, her potential earnings were likely to be outweighed by the expenditure of hiring a helper (2/3 of her previous salary) and thus employment would not have increased the household income.

For Korean families with a disabled child, the major financial difficulty stems from the very high expenditure required to meet the child's special needs. As widely

noted, the extra costs associated with caring for a disabled child, such as the provision of special clothing, transport or dietary needs, have a substantial financial impact upon a household (Baldwin 1985; Read and Clements 2001). Because the Korean state has not yet embraced policies to compensate for such impairment-related costs, many families, especially with those with a severely impaired child, experience severe financial constraints (KIHASA 2002).

Children with a severe impairment are more likely to receive special medical treatment that may not be necessary for non-disabled children. They may also need special equipment or aids in order to maintain a good health status or facilitate their engagement in ordinary activities (Beresford 1995). However, as a number of Korean documents have consistently reported, such additional expenses are rarely covered by the national health insurance system (Byeon et al. 2003; KIHASA 2002). The following account by a father of a child with a severe physical impairment shows vividly the extreme financial hardship entailed by meeting such special needs:

To buy a special mouse for him isn't easy. He can't enjoy other activities because of his physical condition. For him, a computer is essential and buying the mouse right now is my responsibility as his father...but it costs about 2,000,000 won [£1,000], while the mouse people use only costs 7,000 won [£3.5]...Min-a needs a special chair...if he had to sit in an ordinary chair, his body could be easily deteriorate. We need to buy the special chair urgently...but because the cost isn't covered at all by our health insurance...it's too expensive...over 3,000,000 won [£1,500]...Min-a will have to have an operation at the end of this year because his limbs are twisting more and more...another parent told me it would cost over 20,000,000 won [£10,000 pounds]...To do it all, we've no option but to borrow money from a bank...

[Jin-seok]

Jin-seok's 8-year-old son, Min-a, had a severe physical impairment. Min-a could

barely move his limbs and had difficulty even in crawling. Despite the severe restriction of his bodily function, Jin-seok said, Min-a possessed a high level of intellectual ability and was fond of playing a computer game, *Paduk* [Oriental chess], and chatting via the Internet. Jin-seok was working as a middle-manager in a big IT company and earned a relatively high income by Korean standards. However, because there was no welfare support to meet his child's multiple needs, he had to face substantial financial constraints in fulfilling his parental responsibilities towards his son.

The most common and consistent theme arising from the interviews with the parents was the financial burden related to accessing services for their disabled child. The parents referred particularly to the costs incurred by accessing services that were seen as essential in helping their children experience a reasonable quality of life. One mother said:

I've been going to private physiotherapy twice a week...it costs me about 600,000 won [£300] a month...it's so expensive...I prefer to get speech therapy at the SWC [Social Welfare Centre] because it's a little cheaper...anyway, I spend almost 1,000,000 won [£500] a month just on using such programmes...in addition, there are transport costs and regular medical costs...Now isn't the time to save money...we're lucky not to have any debts so far.

[Da-hee]

Da-hee's 11-year-old son has CP (Cerebral Palsy); he has severe mobility impairment and has always used a wheelchair. He experienced difficulty in balancing his upper body and some communication problems. Da-hee said that the primary purpose in receiving professional therapeutic programmes was to prevent her son from experiencing stiffness in his leg muscles and to sustain his general good health. Like

other parents, she considered the regular provision of services as a core dimension of her responsibility in fulfilling her child's special needs. However, as she mentioned, the continual high cost of using such services had been a particular threat to her family.

Because there is no financial support available from the state, these services have to be purchased by parents out of their own finances. Previous research has reported that families with a disabled child spent, on average, almost 'a third of the total household income' in purchasing services (Lee and Lee 2000). This was also generally confirmed in this study.

RESTRICTED COPING STRATEGIES

As illustrated above, financial hardship was one of the most significant practical problems with which parents were continually struggling in their everyday lives. Very many parents found that the struggle to meet the disability-created costs and provide services directly related to the child's special needs was a 'daily battle to be good parents' (Holloway et al. 1997). In an unsupportive social environment, the parents had to deploy their own specific coping strategies in order to create a more favourable situation for meeting their child's needs. Three main forms of coping strategies, even if not always successful, were prevalent: (a) resource augmentation; (b) the minimisation of household expenditure; and (c) the deliberate management of services.

When the existing material resources were scarce, the augmentation of the family resources through the maximisation of the household income was one parental strategy. In particular, for the bread winners who had non-professional jobs, taking additional jobs or doing overtime was inevitable if they were to fulfill their sense of parental responsibility. For example, one father said:

I take a day off on Sundays. On Saturdays, I work until 5 p.m. Usually, I do a night shift for 70 to 80 hours in the month. It's almost noon when I get home. It's very hard work...but I think it's my duty as a father...Otherwise, my household couldn't cope with the costs for the child. And, I can't even dream of other social activities. Since he [the disabled child] arrived, there's no time to meet friends.

[Jin-ho]

Jin-ho was working as a motor mechanic. He believed that his son's continual use of rehabilitation and other educational programmes had facilitated the development of his potential capacity. His son had relatively mild CP and usually used a wheelchair but he had begun to stand up, using a walker. He did not expect that his son would ever walk like a 'normal' child but continual physical therapy was expected to enhance his bodily strength and maintain a better health status. During the interview, Jin-ho expressed his pride in his son's achievement in elementary school and his intellectual ability. However, he commented that his son experienced disadvantages compared to his non-disabled peers because of the dearth of support for extra educational aids. Thus, he identified providing for those needs and continual services for the child's further development as his primary parental role. Jin-ho seemed to have high self-esteem about his own efforts to meet his son's needs and experienced low stress despite working such long hours. However, without neglecting his

resilience and efforts, we need to consider his own trade-off in fulfilling his parental responsibilities. He was highly vulnerable to physical fatigue and, as he mentioned, he had had to give up participating in social activities that are taken for granted by other parents.

The mother of a 6-year-old daughter with severe CP talked about her husband's overworking, which was essential in view of the cost of services and regular medical treatment:

I'm always so grateful for my husband's efforts. He loves our daughter so much, but I'm worried about his health. He works too hard...In fact, my husband's salary from the bus company isn't enough...as you know, it costs too much to rear our children...Though he says 'Don't worry, I'm a strong man', he actually doesn't have time to take enough rest...He drives a taxi at night too...two or three days a week...it's almost one o'clock when he comes home.

[From field note, 13-01-2004]

The maximisation of the household resources by taking on extra jobs or working overtime was not always possible for the bread winner because of the high demand for physical sacrifice or different employment status. For non-disabled families, the augmentation of their material resources through the mother's participation in full- or part-time work may be one way to manage the risk of financial hardship. However, as discussed earlier, this option was rarely available for families with a disabled child. Therefore, many had to choose a very defensive strategy. When they discussed their day-to-day lives, a great number of the parents said that the minimisation of the household expenditure had been inevitable, given the need to provide continually for their child's special needs. For example, Ji-weon described the change in her family life as follows:

We've no way to earn money except through my husband's salary. If we want to save money, there's no option but to reduce our daily expenditure. To speak frankly, whenever I buy anything, I try to find something cheaper...Looking back, it seems that I was really rich before [laughs]...I didn't think twice about buying fancy clothes and famous brand cosmetics...but now I hesitate to buy even basic lotions and toners...My husband also seems to avoid meeting his friends. He used to be someone who really liked going out with friends, but now it seems he is very reluctant to go out drinking.

[Ji-weon]

Ji- weon's husband had worked as a supervisor in the construction industry and her family was middle-class in terms of household income. However, like many other parents, they found that meeting their child's special needs a financial burden. Ji- weon stated that almost half of her husband's salary had been spent on providing good quality services for their 8-year-old son, who had profound communicative and behavioural problems. In order to manage her family life without cutting down on the services and programmes her child needed her family had to reduce expenditure on both their daily living and social activities.

Regardless of their child's age and impairment, securing the continual provision of relevant services to develop the child's potential ability and give opportunities to engage in ordinary social activities was a central concern of the parents in this study. Given that all services to cater for the child's special needs had to be privately purchased at a substantial cost to the families, they emphasised that the rational management of services within their existing material resources as an important coping strategy. One mother commented:

Mothers prefer to use the programmes offered by the SWC. Otherwise, we

have no option but to use private institutions, but, as you know, it's so expensive. So mothers have to be persistent if they want to get a place on a the programme...in my case, I always put my child's name on the waiting lists of at least three different SWCs.

[Yang-hee]

In a sense, seeking out services is a life-long career for these parents. Facing both a lack of service resources and financial hardship, the parents' commitment to their child's welfare demanded them to engage in continued, intensive searching. It was a stressful but 'active process of juggling and piecing together' (Daly and Leonnard 2002). Seeking good quality services at a relatively low price, prioritising the child's special needs and finding the optimal line between the costs and effectiveness of services characterised their day-to-day struggle.

UNSHARED CARE

Caring for a disabled child is an integral part of the parents' daily lives. As widely noted, the management of care work is mediated through the provision of care support, in both formal and informal ways (Baldwin and Carlisle 1994, 1999). Good formal care services, such as nursery schools or day-care programmes, can be a beneficial resource for families with a disabled child, enabling them to reduce their stress and enhance their well-being (Beresford et al. 1996; Sloper and Turner 1992). They can also offer the disabled child the chance to learn and socialise outside the home (Read and Clements 2001). However, for a number of families in this study, the chance to use such formal care services was unavailable or highly limited. For

example, some mainstream nursery schools discriminated against disabled children and denied them access:

When my son was six, I tried to send him to nursery school. The mothers I met at the private therapy clinic told me it would be good for his development. So I visited three nursery schools, but they all denied him admission. One principal rejected him out of hand, you know, without looking at my face: 'We know about such children, but we can't take him'...at least, it's his responsibility to explain its' difficult, isn't it?...I was really upset...On the way home, I kept thinking 'Because I'm the parent of a disabled child, they don't treat me as human'.

[Yun-seo]

Even when the child is granted access to mainstream nursery provision or playgrounds, the parents frequently endure additional burdens. Another mother commented:

Because Jun-a had no experience of playing with other [non-disabled] children, I wanted to send him to nursery school...But the principals of two nursery schools denied Jun-a admission...Only one nursery school accepted him on the condition that I would send him with a helper who has a degree in special education...

[Yang-hee]

Like Yun-seo, Yang-hee's purpose in using the formal care services was not simply to alleviate her own care work. She wanted to give her son more opportunities for social interaction with non-disabled children as he moved on to primary school. However, since mainstream nursery schools could not provide any support for her son, who had a physical impairment, Yang-hee had to hire a helper at her own cost. Thus, for her, using formal care services meant shouldering another burden.

Some parents may prefer to use more specialised care institutions because

their child needs more sensitive, skilled attention. While the number of specialised care centres or day-care programmes for disabled children has gradually increased over the past decade in Korea, the availability of services remains very limited (Y. Kim 2003). The issue of restricted access to care services was raised by a number of parents. The following mothers' brief comments identify the most common difficulties:

- 'Mothers have to wait for two or three years to use the programmes offered by the SWC'
[Tae-hee]
- 'It strictly limits the period of using the day-care programmes to one year'
[Min-joo]
- 'There is no day care centre near to my house. If I am going to use it, I have to drive for about an hour and a half'
[Jeong-eun]

Besides these objective barriers to using the formal care services, some parents stressed that families with a severely impaired child are frequently excluded from those services. One mother commented:

Once he'd finished the infant classes offered by the cerebral palsy organisation, there was no place to send my son...when a child has a severe impairment, like my son, we can't send him to day care in the SWC...They won't accept our child...if you go there, you see that one teacher is looking after five or six children...the only children there are ones with a mild impairment.

[Ji-soo]

Ji-soo's narrative reveals that the institution established to provide care services for families with a disabled child was a site in which another form of discrimination was

created. Eligibility to use the service is determined by the support needs of the children and their families.

These factors combined led some parents to feel that the existing services were inappropriate for their child and their family and, as a result, they had to commit themselves to the almost constant care for the child. Unsurprisingly, this restricted the possibility of the parents, usually the mother, having the time to engage in social activities. For instance, Ji-min said, 'Before my son went to school, I never had lunch with friends'.

A number of studies on families with a disabled child have focused on the benefits of the informal support provided by the extended family (e.g. Beresford 1994; Parker 1992). The care support given by extended family members was also reported in this study as beneficial to managing the family. One mother said:

I couldn't say in a few words how much I owe to his grandparents. They really cared for my son well...with loving hearts...they did better for my son than I did...To speak frankly, I'm not lying when I say that I never had any stress while rearing the child.

[Jea-ok]

Jea-ok, the mother of a child with a mobility problem and learning difficulty, had received continual care support from a very early stage. She greatly appreciated the fact that her parents-in-law had shared substantial amounts of practical caring work as well as providing emotional support. Unlike the situation in other families, this enabled her to continue to work without experiencing any difficulty in managing her childcare.

However, Jea-ok's case was exceptional in the present study. Continual and

practical support from the extended family members was usually unavailable. In addition to the objective barriers, such as the physical distance from the extended family, there were several factors that made the parents reluctant to share the childcare with the extended family members. Two mothers mentioned that the grandparents' overprotective attitudes towards their children, which were likely to reduce their child's sense of independence, made it difficult to share childcare with them. Many parents regarded their children as more vulnerable to events or accidents that might cause physical injury or emotional upset. They saw caring for a disabled child as a quasi-professional task, which necessitated competence in meeting the child's special needs. Accordingly, such parents felt that it was difficult to find others in their informal networks who were as competent as themselves to care for their child. Some parents explained that it was difficult to accept informal care if there were no means of reciprocating:

I don't want to ask my siblings or my husband's siblings to care for my child...They're all good people, but I don't want to burden them...it isn't good to receive help and not give any in return...If it's not an emergency, I try not to ask for their help...I feel more comfortable asking a mother of another disabled child who is close to me.

[Ka-yeon]

Many parents were also conscious that their relatives or others close to their family might regard caring for their child as only physically demanding. Linked to this was a concern that their child should not be seen as a 'burden':

Asking relatives to look after Min-a isn't easy...feeding, toileting...he needs so many helping hands...If people aren't used to doing those things, they get tired easily...I don't want to see them get frustrated by my son...they'd feel

that caring for him is just a burden...

[Jin-seok]

As a whole, these factors can be thought of as an 'indirect barrier' to using informal care support (Beresford 1994), and constituted the reasons why the parents preferred to use formal services rather than informal support.

THE PSYCHO-EMOTIONAL EFFECTS

Thomas (1999) suggests that the experience of disability entails damage to one's psycho-emotional well-being. This notion can be also applied to the parents' experience of disablement. As discussed before, parents are likely to sacrifice their ordinary social activities that are taken for granted by others. As widely noted, the restricted chances in their social lives often damage their sense of self and quality of family life (Read and Clement 2001). Whilst many parents had shown their resilience in solving practical problems, it was also true that many were living with feelings of insecurity and vulnerability. Worries about money, employment problems, and other material problems were deep-seated when talking about their daily lives:

... Rearing a disabled child is like throwing water parched soil. There's no time to save money...someday I might get ill...if it happened, how would my family cope with the problems?...if I think about it, I can't sleep...

[Jin-seok]

Many parents of disabled children reported the difficulty in sustaining

balanced relationships between waged work, domestic work, caring work and the needs of the family members. In fact, the parents' day-to-day family life management entails exclusion in certain ways. They have to trade-off their own and other members' needs to meet the essential needs of their disabled child. Whilst the parents wished to fulfil their parental duties to all of their children, they also felt compelled to choose one child's needs and thus sacrifice the other child(ren)'s needs. For example, one mother commented:

It seems that my second [non-disabled] daughter would like to take piano lessons. Among her friends in this apartment block, she is the only one who doesn't have them. She seems to feel different from her friends. Always such decisions...The fact that I can't do enough for her breaks my heart...I'm very sorry for her...but if she had the lessons, my son would have to abandon one of his programmes.

[Eun-kyeong]

Like other parents, the parents of a disabled child want to do the best they can for their daughter or son. The inability to provide for the child's needs made the parents feel guilty and inflicted significant psycho-emotional damage.

In addition to financial vulnerability, health was a main concern for almost all parents. The amount of direct caring work with a disabled child can be greater and more complex than with those without an impairment and may persist for many years. Indeed, caring for the child can become increasingly difficult as the child gets heavier and the parents grow older (Twig and Atkin 1994). The parents identified their care work as a 'marathon'. The risk of physical and emotional burn-out was a deep-seated concern for many parents. On top of the difficulties of caring for a disabled child, the pressing needs of other family members can make the family

more vulnerable. Further, unsupported caring can create physical illness and emotional distress, which can result in the carers themselves needing care. Je-ook recalled:

It was a very difficult decision [to send his daughter to a residential institution]...I tried a lot of places, but there was no place that would care for my daughter all day...my wife needs rest...if I had enough money, I might leave my job...It was like choosing between killing my wife and my daughter...I really didn't want to send my daughter there...but, at that time, we had no choice...what can I say?...it was like abandoning her.

[Je-ook]

Fortunately, his wife recovered and his daughter returned from the residential institution after three months. Je-ook's experiences show well how the family of a disabled child is likely to break down in a society where care is not shared.

THE SUBJECTIVE MEANINGS OF CARING

The parents' accounts of caring were not always focused on the difficulties; they also contained descriptions of the rewards such caring brings. It seems that, despite the variation in experience, most families developed ways of working collaboratively. Similar to the findings of previous research, the enhancement of mutual understanding and intensification of communication were identified as the rewards when many of the parents in this study described the changes in their marital relationship after having a disabled child (Bower and Hayes 1998; Ferguson et al. 2000).

Caring for a disabled child can create physical and emotional demands that exceed what is usually required of the parents of non-disabled children (Twigg and Atkin 1994). However, it would be a mistake to assume that the parents characterised their child as a 'burden' to be shouldered (Hornby 1992). While they talked about the stressful, demanding aspects of their day-to-day caring, almost all of them insisted that their disabled child had been a vital resource in coping with their problems. Indeed, these children were a real source of pleasure to their parents, which helped to lift the parents' spirits and boost their morale:

As a child grows, he does so many cute things...you know, things I could never have expected or imagined...To anyone else, it might seem like nothing...But it's so lovely to me...My son likes digging into the soap and squeezing the toothpaste...One day he was in the toilet and I thought he was playing with the soap, so I said 'Ho-jin, don't play with the soap. It'll melt'...but he didn't answer. I went to the toilet and checked the soap. It didn't seem to be any different...but when I went to use it a while later, I found it was broken...he'd actually dug right into it and turned it over [laughs]...In fact, he makes a lot of mischief but what he does is so funny and lovely...Things like that are like vitamins for our family.

[Ji-min]

Ji-min's son had an intellectual impairment and experienced some behavioural problems. Like many other parents, she appreciated that caring for the child was a process of the development of a special inter-relationship and of family bonding. As her disabled son grew, she formed an intimate relationship with him. Rather than seeing the child as simply a dependent to be cared for, through building a reciprocal interaction, Ji-min also received emotional resources enabling her to alleviate the hardship associated with day-to-day care work.

The parents' appreciation of their disabled child's unique characteristics and gradual construction of a special inter-relationship will not simply be a psychological defensive mechanism in coping with problems with the child. It facilitates parents to come to understand their child's impairment from his or her perspective. Ji-min states:

In the beginning, because everything was different from other children...I thought...he wouldn't know anything, but it wasn't true. He had the same desires, felt everything like we did...but he just couldn't express what he thought or wanted in detail...I felt sorry that I hadn't understood that about my child...in the early days, to be honest, I thought... 'It's painful to see him and to feel distressed every day. He knows nothing and he'll just be happy if I do everything for him'...But as I brought him up, I came to see that he too was experiencing difficulties in his own way.

[Ji-min]

By getting to know her child, Ji-min came to perceive the child's impairment as a crucial component which could not be separated from his whole personhood. This process enabled her to develop reflexive thought about her previous ideas of 'difference'. Tae-hee's narrative provides another example from the time when her son was seven-year-old:

It was so stressful...I struggled to teach him how to add and subtract simple numbers. I tried to explain again and again in the easiest way but he couldn't understand it...I got angry...it was like I was going crazy...I had to go out to the kitchen to get some cold water and calm down. I came back after a few moments, all set to try again...but you know what happened?...the book was changed...it was a cookery book. In fact, it was his favourite...he was telling me 'Let's do what I do well' [laughs]...He liked cooking. He does it well now...When I understood that, I saw it was funny...so many thoughts came together...Why should learning calculation be so important to him? Wasn't I trying to teach it by force so I wouldn't hear other people say 'Your child is stupid?'

[Tae-hee]

During the interview, Tae-hee identified this moment as a 'true acceptance of her child'. Her account suggests that the parents gradually perceive the child's impairment as an essential ingredient of their children's personality. The development of inter-subjectivity on the basis of intimacy made her recognise that her son's unique characteristics and tempo, enabling her to transform her previous perceptions of normality.

DEALING WITH NON-DISABLED SIBLINGS

The brothers and sisters of disabled children experience a secondary form of disability (Burke 2004). As several writers have pointed out, the negative perceptions of disabled children are likely to extend to their siblings and, as a consequence, they can experience exclusion or adverse reactions from their peers (Burke and Montgomery 2003; Middleton 1996). This issue was raised by several parents during the interviews. Among others, Ji-soo stated that her older daughter had been bullied by her peers and had been upset during her first two years at elementary school because her classmates had never invited her to their birthday parties.

The experience of secondary disability can lead non-disabled siblings to feel ashamed of their disabled brother or sister:

I took my children to the market to buy groceries...when I started the car, my elder [non-disabled] child suddenly lowered his head. I thought something was wrong with him so I stopped the engine and asked him... he didn't say anything for a while...a bit later, he said that he'd seen his classmate passing our car...I hadn't expected that...because I believed he liked his brother and they got on together really well at home... but what he

felt outside was different...it was nothing to do with how much he liked his brother...

[Tae-hee]

The negative images imposed on disabled children may influence their non-disabled siblings to the extent that they perceive their family as 'less than normal':

One day...when he [the elder non-disabled son] was nine years old...we were watching television together...the drama was about a disabled man's life...he suddenly said to me 'Mum, I'd marry the sister of that man because his disability worse than my brother's'...I asked 'Why do you say that?'... His answer really shocked me. He said, 'If I did, she wouldn't look down on me'...

[Yun-seo]

Yun-seo's story shows how non-disabled siblings internalise the negative meanings given to an impairment as their own. It was obvious that her non-disabled son regarded having a disabled brother as a mark of inferiority and thought that to marrying someone whose sibling had a more severe impairment than his brother was a way to avoid having his wife despise him.

Many parents learnt that they had to undertake additional roles to provide new cultural capital for their non-disabled children. They usually chose to explain the characteristics of the specific impairment and emphasise the positive side of disabled people's family life in facilitating the non-disabled child's understanding of disability. Jeong-hee recounted:

From early on, I tried to explain again and again her young brother's impairment...we talked about him a lot, like why he acted like in certain ways and the ways in which we cared for him...she seemed to understand that it [impairment] can happen to anybody...One day, we were watching a

TV programme dealing with the disabled people and their families...I explained that there are lots of disabled people like her brother...and their families live happily, like other families...I believe my daughter has a positive sense...actually she isn't reluctant to talk about her brother's disability with her friends...Now, in her class, one classmate has learning difficulties. She's a volunteer helper for this friend.

[Jeong-hee]

Jeong-hee's son has learning difficulties and is six years younger than her daughter. She has tried to explain as often as possible to her non-disabled daughter the reasons why her disabled brother acts in unusual ways and how she could help him. Jeong-hee mentioned that she has tried to make her daughter understand that her disabled sibling's impairment is not something shameful and that her family is not 'abnormal', just different. Jeong-hee sees this daily communicative education as protecting her daughter from the potential emotional damage caused by others' attitudes and also as encouraging her self-esteem. At the time of the interviews, Jeong-hee seemed to be very proud of her daughter, who was acting as a volunteer helper for a disabled classmate.

The parents also tried to help their non-disabled child to develop the confidence or strength to handle negative reactions. Dong-keun's narrative reflects this well:

I tried to get my daughter to read books about disabled people and told her about other disabled children...since she was a child, I haven't hesitated to take her along to the campaigns and organisational events to let her see...Now my daughter is in year 4 of elementary school and my disabled son is in year 2 at the same school. When her brother went to his new class, she went too and explained his disability to his friends, and she also took him into her class and said that he was her brother and explained his impairment...It seems she's not at all ashamed of him.

[Dong-keon]

Dong-keon's case was exceptional in that he had been involved in the parents' activism from the very early years and had prior experience of political movements. However, his efforts to mitigate his non-disabled daughter's self-stigma and increase her self-esteem were also similar to those made by a considerable number of families with a disabled child who had one or more non-disabled siblings. From the start, Dong-keon tried to help the non-disabled child understand that her brother was disabled by chance; therefore, he should not be ashamed or blamed by others for his impairment. By taking her to various events held by disability movement organisations so that she could see disabled people struggling for their rights, he intended his daughter to feel, although she was still too young to understand fully, that her disabled brother had the right to live his life as the equal of others and that he should receive the necessary help from others to live an equal life. Like Jeong-hee, Dong-keon evaluated his own early efforts to instil strong positive and critical thoughts into his non-disabled child as successful and was proud that his daughter had become an advocate for her disabled sibling.

SOCIALISING OTHERS TO ACCEPT THEIR CHILD

Given that they live in a society where the disabled child is devalued, many parents felt that they needed to play additional roles in order to 'socialise others' so that they would accept their disabled child (Kittay 1999). In order to facilitate their child's acceptance, the parents developed their own tactics. The parents felt that they needed to engage in perception management in order to 'see' the child rather than simply the

impairment:

When we go out, I always try to make sure my child's well dressed...even though we may only be going to buy something at a shop very near our home...I don't want to have other people think he's from a poor background ...If he isn't well dressed, I believe, people won't like to look at him. My son looks really charming when he's well dressed. Everyone says 'He's so cute and handsome'...they like to touch his hair and say 'Hi' to him...it's just the way people think...

[Soo-hyeon]

The parents' actions regarding the manipulation of their disabled child's appearance can be regarded as 'compensatory practices' for upholding their child's worth and personhood under the dominant view of disabled persons as social burdens (McKeever and Miller 2004: 1187). Their engagement in perception management often extended to the careful manipulation of their own attitudes or behaviour. Jeong-eun's narrative illustrates this well:

I usually say hello first before they ever see us. I think we need to do that for several reasons...If we're on our best behaviour, they'll accept my son and his strange ways more easily...And to make them understand our child's disability better, above all, we, as his mother and father should be friendly and polite to others, and more frequently than they are to us.

[Jeong-eun]

Like many parents, Jeong-eun firmly believed that others' concerns about and reactions towards their child are mediated through their parents' own relationships with others. In the case of Jeong-eun, the symbolic manipulation of her own behaviour was employed to facilitate others' understanding of her disabled child.

As their disabled child grew up, many parents felt that they needed to adopt 'diplomatic roles' in order to secure their child's safety and facilitate his or her acceptance (Read 2000). Significant numbers of parents employed a similar strategy, what one interviewee described as 'revealing first': explaining their child's 'impairment to others and alleviating the stigma imposed on the disabled child. Ka-yeon's narrative provides a good example of this:

A few days after I moved here, I hosted the *Pan-sang-hwe* [monthly meeting with neighbours to discuss certain community issues] in my home. I explained that my child had autism and sometimes behaved in unexpected ways...he wouldn't be doing it on purpose...then I introduced my son to them...Whenever there was a meeting, I'd take him there so others could see and experience him...now, anyone who doesn't know my son is probably a spy [laughs].

[Ka-yeon]

As shown in the narratives above, the parental management of others' perceptions of their own child in their daily lives was not simply a defensive reaction. Whilst their specific actions varied, it can be understood as a process of developing a 'safe zone' in which their disabled children are protected and, at the same time, increasing 'the wise group' who accept the child despite of his/her difference.

CONCLUSION

This chapter has examined the difficulties and dilemmas that the parents encounter in the management of their daily family lives. The combined effects of the restriction of the household income and extra costs pose a particular threat to their family's

economic well-being. In particular, the parents in the study have commonly experienced material hardship in relation to providing for their disabled child's special needs and services because there is no financial support available to cater for such needs. The issue of unshared care was a consistent theme in the parents' accounts of their daily lives. They have experienced difficulties in accessing mainstream or special care services. Whilst many parents have developed their own resilience in solving practical problems, it is also true that they experience unequal chances to participate in social activities. In exploring these practical problems, I also highlighted the psycho-emotional damage that many parents had experienced. This chapter also examined the additional parental roles that they play in order to manage the stigma associated with their disabled child, and also how this affects their non-disabled child(ren).

Schooling is another crucial dimension of the parents' daily lives. In the next chapter, I will examine the parents' involvement and experiences in the school setting.

CHAPTER SIX

PARENTAL EXPERIENCES AND PRACTICES AT SCHOOL

INTRODUCTION

This chapter presents the parents' accounts of their experiences and practices with regard to their child's schooling. It firstly provides a historical overview of the development of educational policies in Korea. This is necessary because, during the last few decades, Korea has witnessed rapid changes in its policy agendas and in the discourses regarding 'special' education, and the establishment of programmes for disabled students. Indeed, the parents' experiences and accounts cannot be understood in isolation from such changes.

The overview will be followed by a close examination of the parents' struggle in schools and the salient features of the discriminations, inequalities and exclusions that disabled children, and their parents by association, experience in the school setting. In doing so, as well as using the interviewees' narratives, I will draw on various resources obtained during my fieldwork. The chapter will finally pay attention to the mediating roles that parents play in facilitating their disabled child's friendships and in socialising his/her non-disabled peers.

A HISTORICAL OVERVIEW OF THE DEVELOPMENT OF SPECIAL EDUCATION IN KOREA

From a historical perspective, Christianity has played a central role in the development of 'special' education in Korea. School-based special education programmes were first introduced in the 1890s, when Christian missionaries began to teach blind people (S. Lee 1995). As part of their aim to encourage Christian philanthropic special treatment of disabled people, they established Korea's first (modern) special school for blind and deaf children in 1909. This provided a model for the subsequent education of disabled children. Even during the period of Japanese colonisation (1910-1945), a number of Korean priests and Christian educators played pioneering roles in developing curricula and materials designed for disabled pupils (S. Lee 1995).

After Korea gained its independence in 1945, Christianity began to establish impairment-specific special schools in the main cities. At this time, disabled children's education received scant attention from the national government, so the special schools built by Christian groups were the main education providers for school-aged disabled children until the late 1960s (B. Kim 2003). There are no official statistics for the level of attendance of disabled children in mainstream schools. However, given the lack of attention to disabled children in the educational policies, except for the very small number of pupils with a 'mild' impairment, the majority of disabled children were unable to access the mainstream educational settings (B. Kim 2003). This minimal provision of educational opportunities for

disabled children as a whole can be imagined from the number attending special schools at this time: only 1,343 disabled pupils were enrolled in 12 special schools in 1962, and 3,121 disabled pupils in 22 special schools in 1967 (MEHR 2000). Thus, the main public issue throughout the 1970s was focused upon the urgent need to enhance disabled children's access to educational settings (Hahn 2003b).

The enactment of SEPA (Special Education Promotion Act) in 1977, which provided the legal basis for the state to improve disabled children's access to special education, was an important turning point in Korea (Park 2002). As the term SEPA implies, government policy regarding disabled pupils focused upon increasing the number of institutions and agencies delivering special educational services. In addition to establishing publicly-funded special schools, the government encouraged the establishment of privately-funded special schools by offering financial support and administrative incentives. As illustrated in Table 2, this policy contributed to the steady increase in the number of special schools:

Table 2 The growth in the number of special schools

Year	1972	1977	1982	1987	1992	2000	2005
Schools	38	51	65	95	103	129	142
Pupils	5,188	7,342	10,679	17,373	20,690	24,196	23,449

[Source: adapted from MEHR 2000, 2005]

Another key government policy after the enactment of SEPA encouraged the growth of 'special classes' [i.e., specially-equipped classrooms] in mainstream schools. The steep numerical increase in the number of special classes in the 1980s

was one of the significant features of the development of special education in Korea (see Table 3).

Table 3 The growth in the number of special classes in mainstream schools in the 1980s

Year	1974	1980	1982	1984	1986	1988
Class	210	355	521	946	2,361	2,810
Pupils	4,418	6,045	7,655	14,087	30,876	33,660

[Source: ME 1998]

However, the increase in the number of special classes in mainstream schools during this period did not signify integrated/inclusive education. It was primarily driven by economic considerations; that is, by a desire to avoid the much greater costs of establishing special schools (B. Kim 2003). From the start, special classes for disabled children were perceived as a part of a special education system rather than an integral part of mainstream education. Indeed, throughout the 1980s, special classes in mainstream schools were operated full-time, and were self-contained and segregated from the rest of the school (B. Kim 2003). One scholar identifies this period as ‘implanting a secondary form of institutionalised, segregated special school into mainstream schools’ (S. Park 1994).

The emergence of a disabled people’s educational rights movement in the early 1990s contributed to the amendment of the SEPA in 1994 (Park 1996). The revised law became the foundation for the special education reform and provided the basis for the government to improve educational services for disabled pupils. In this law, ‘the purpose of special classes is to facilitate inclusive education’ was clearly

stated for the first time. The responsibilities of the local government with regard to promoting the provision of educational services for disabled students were also identified, as well as the contents of the 'special educational programmes' and the procedures of inclusive education (Park 2002).

While Korea has witnessed substantial growth in 'special' educational services since the 1990s, many problems remain. The rhetoric of inclusive education and disabled pupils' right to education has seldom been translated into reality. School professionals in many mainstream schools are unaware of or are antagonistic towards inclusive education (Park 2001; Shin 1997). Many special education professionals hold the view that the benefits of an education in a segregated special school outnumber the harmful effects, arguing that mainstream schools do not have the capability to serve disabled pupils' needs (K. Kim 2001; I. Lee 2001). Despite the amendment of SEPA in 1994 and the subsequent legal support for inclusive education, special education has been separated from the general educational system, and services for disabled pupils are still mainly provided by special schools (H. Kwon 2005; Park 1999, 2000).

DEEP-SEATED DISABLING ATTITUDES

The perception and knowledge of disability held by school professionals comprise a firm foundation for the ways in which pupils with an impairment are treated (Carrington 1999; Hegarty 1993). A positive attitude on the part of the school

professionals involved with disabled children's education can effectively set the pace for the realisation of the child's full potential. In contrast, the teachers' negative attitudes are likely to have an adverse effect on the child's total school adjustment, self-esteem and the other, non-disabled pupils' reactions to the child (Vlachou 1997).

Whilst the parents in the present study mentioned examples of some teachers' positive attitudes and sympathetic support, they reported that their child had been generally treated negatively and differently from the other pupils. The parents' experiences reveal that the schoolteachers' negative attitudes and reactions were closely associated with, and reinforced by, a number of related disabling cultural practices, such as the stereotyping, stigmatisation and negative categorisation of disabled people (Middleton 1996, 1999). For instance, the mother of a son with autism described how his impairment was portrayed negatively by one teacher who displayed disabling attitudes:

...One day, she called me and said I must come to school immediately...According to her, my son was touching his trousers around his penis repeatedly in class...when she mentioned it, I immediately knew why he'd done that...he couldn't bear getting wet...I thought, he must have done it because he felt his underwear was wet after having a wee...so I tried to explain...but she didn't seem to believe what I was saying...what shocked me was that she came right out and asked 'Has he a sexual perversion?'... Since then, she's been continuously looking at my son suspiciously all the time, as if he were likely to sexually attack the girls in the class...she wasn't interested in my explanation...

[Soo-heyon]

Soo-heyon's story reveals how a child's impairment can be given a distorted meaning by a teacher who is prejudiced against disabled people. Despite the mother's efforts

to help the teacher to understand the child's behaviour in the light of his impairment, the teacher saw his behaviour as a sign of sexual deviance.

Some of the parents reported that their child's difference was always negatively perceived and became a reason for blame. Jeong-eun's narrative illustrates this well:

The teacher I met in year 5 [at elementary school] had no basic quality as a teacher and no common sense...He always described my son as a troublemaker...I know my son's behaviour does sometimes interrupt other pupils, but it's very minimal. If you say to him 'Sit down on a chair', he usually does it...but the teacher was always complaining that my son was a disruptive influence in class...I'm not saying this just to defend my son...honestly, I always participated in the class in the early months of each school year to help my son adapt to a new environment. So I know the class environment well...In fact, other children make the teacher's life difficult and mess around in class...they talk to each other, fight and ask the teacher ridiculous questions, but those children's behaviour was regarded as exceptional...Only my son's minimal interruptions were a problem.

[Jeong-eun]

The stereotyping and stigmatisation of disabled pupils was also expressed in the school's direct discriminatory practices. The disabling attitudes held by the head teacher were a particularly significant barrier to promoting an inclusive school culture. One mother, who had participated in a parents' forum, reported:

My daughter is now in a special classroom along with seven other disabled children. They all have mild impairments. But those children haven't participated in general classes...We and the special teacher doesn't think there's any problem in our children studying with other [non-disabled] children in regular classes. So we asked the head teacher several times to allow our children to join regular classes...but he wouldn't accept it...he just kept on repeating the same words...'They can cause accidents...They'd disturb the other children's studies'...he even urged the [special] teacher not

to do outdoor activities...the head teacher always sees our children as troublemakers.

[From field note: 10-3-2004]

As this mother's narrative illustrates, the head teacher acted as an agent in maintaining the boundary between disabled and non-disabled pupils by categorising the former as a dangerous group. It is not difficult to recognise that the head teacher perceived disabled pupils, regardless of their specific impairment or individual characteristics, as a homogeneous group in the sense that they all disturb the 'normal' pupils' schooling.

Given such unfavourable circumstances, for many parents, keeping their child in a mainstream school was a stressful daily battle against the teachers' negative attitudes:

During the first year [of elementary school], I was crying so much because of the ways the teachers treated my son. They seemed to be obsessed with how to move him to another school...they used to spit questions at me like...‘Why don't you go to another school?...Why are you making it hard for yourself?...Isn't there a special school for your child?’...Because, at that time, I really wanted to educate my son in the [mainstream] school, I put up with such attitudes...hoping that someday their attitudes would improve...but it was too stressful...I always had to say as if I was begging...‘I'm sorry about my child...Please accept him’.

[Yun-seo]

The parents' most painful experience was that their children did not receive even minimal respect in their relationship with their teachers, let alone supportive help.

One mother told her painful story:

It was heartbreaking to hear that [pause]... the teacher didn't say her name even once during the last three months and never tried to encourage her to participate in a play group... Even though my daughter has some difficulty in speaking, she's intelligent... but the [home class] teacher even said to her 'Don't exchange books with anyone. Just read yours'... She has difficulty in controlling her mouth muscles, and sometimes dribbles...but how could he say that as a teacher in front of her classmates?

[From field note, 16-4-2004]

I met this mother at the parents' organisation where I worked during the fieldwork. Her daughter was in year 4 at a mainstream school and had CP (Cerebral Palsy). Her husband had passed away a few years before from cancer and she had had to take a paid job. Thus, she could not be as actively involved in her daughter's schooling as some of the other mothers. It is not difficult to imagine that such daily degradation by the teacher damaged the child's self-esteem and engendered feelings of isolation and segregation.

Of course, the parents wished that the teachers would have more sympathetic, supportive attitudes towards their children, but what they learnt through their interactions with the schoolteachers was that:

It's like winning the lottery to find a teacher who really accepts disabled children.

[Soo-heyon]

In their experience, the schoolteachers' disabling attitudes and negative treatment of the impaired child was the norm. As a result, for the majority of the parents in this study, protecting their child from the teachers' maltreatment and dealing with their negative, discriminatory attitudes were the most stressful and

painful experiences associated with their child's schooling.

THE LACK OF PARTNERSHIP

Throughout the child's time at school, the parents come into contact with various school professionals in both mainstream and special schools. Regardless of their specific circumstances, the parents in this study all emphasised that achieving a collaborative relationship between teachers and parents is a precondition for their child's effective educational and social development. However, many parents reported that they had faced significant barriers in building partnerships with, and in receiving collaborative support from, schoolteachers.

Disabling values inflicted upon a disabled child were typically transferred to the teachers' attitudes towards parents. Where the teachers regarded the children as an inferior group or burdensome, they did not welcome the parents into the school and did not regard them as clients. Indeed, a significant number of parents reported that they had been unfairly treated and had not received as much respect as other parents:

Among us, there is no middle class...To be respected by teachers, parents have to be in very powerful social positions such as doctors and lawyers...Otherwise, we are always looked down on just because we are parents of disabled children...Teachers respond differently even when we help with school activities as much as other mothers [of non-disabled pupils]...They hardly ever show any appreciation...even when we help to clean the classroom, they just see it as something we ought to be doing, because our children make things difficult for them.

[Jeong-hee]

It has been widely emphasised that sharing knowledge and information based upon mutual respect constitutes a vital component in developing harmonious, collaborative relationships between teachers and parents (Vincent 1996). This is particularly important for the parents of disabled children (Mittler 2000). Many of the participants in this study believed that their own knowledge and experience could provide an important resource for facilitating good relationships between their child and the teacher. According to Dong-keon:

Some teachers are well informed about my child's impairment and have previous experience of teaching disabled children. But, in general, they have the same knowledge and perception of disabled children as the general population...To help teachers understand my son...in my case, once a class teacher is decided, I call him and ask for a meeting to talk about my son. If he agrees, I show the records to the teacher, explain my son's educational programme so far, why he might behave 'strangely' and how the teacher should respond to this...and I say 'If you have any difficulty in teaching my son, always send me an e-mail or telephone and I will see what I can do to help overcome the problem'.

[Dong-keon]

Like Dong-keon, many parents consider it vital to share their knowledge and experience with the teachers in order to secure appropriate support for and effective teaching of, their child. However, their voices are often ignored, denied and devalued by the schoolteachers. One mother recalled:

...in my case, the class teachers aren't willing to listen to what I'm saying...if I want to talk with them about my child, they refuse; they just say 'I know about such children'...but our children are all different...they have

different characteristics...I'd like to give them specific information and advice about my child, but they don't want to listen to what I have to say... they simply ignore me...When I asked for some time to talk about my son, they treated me as if I were a troublemaker.

[Soo-hyeon]

The parents hoped that they could participate in the decision-making and influence the operation of the educational services. They wanted to play a supportive role or be co-planners in promoting their child's personal and educational development. However, the parents were not always welcomed and considered as partners by the teachers. The parents' efforts to make their voices heard and ensure their commitment to schooling on behalf of their child were often perceived as threatening to the authority of the teachers. Min-joo recounted how teachers in a special school responded to her involvement in the child's education:

Some teachers dislike mothers talking about teaching even though, in fact, we are almost as good as specialists in our child's case, although we don't have a certificate...we know that they may have more knowledge than we have but no one knows our child better than his parents who care for him every day...mothers sometimes feel that it would be better to teach in this way or that way...If we offer some suggestions, they don't like it...One teacher even said to me 'If you know so much, why don't you teach him yourself?'...in fact, I just wanted to help the teacher with my son...but he treated it as interference in his area...We sometimes asked about changing the curriculum, but they didn't take our opinions seriously...they said 'It's not the mothers' business.'

[Min-joo]

A number of parents of children in mainstream schools emphasised that their efforts at mainstreaming the child's education were easily dismissed and even treated as selfish or egoistic behaviour:

Fortunately, I didn't experience it myself...but I heard so many stories...some teachers said, 'I'm so unlucky this year to have to take your child'...They'd say thoughtless things like...'Don't you think you're being greedy, placing your child in a 'normal' school?' 'Do you want your child to stay here and so sacrifice other [non-disabled] pupils?'...Many mothers are very hurt by such word.

[Ji-min]

The parents in general had a realistic understanding that schools have limited resources and expressed sympathy with the teachers' determination to meet the pupils' needs, often despite the poor teaching conditions (for example, large class sizes). The parents also acknowledged that many of the difficulties they were experiencing, such as the unavailability of teaching assistants and personal helpers, could not be solved by the efforts of the teachers alone. Thus, they considered a variety of ways for increasing the support for disabled children through grater cooperation between the teachers and parents. However, the parents argued that there was a significant gap between the parents' and teachers' understandings of the 'responsibility for the disabled child'. The parents saw the teachers as taking minimal responsibility for disabled pupils, but this was frequently denied by the teachers. Many of the parents reported that they were compelled to stay at school and, if not, they were often criticized by the teachers. 'Being chained', as the father (below) puts it, was a widespread phenomenon in mainstream schools and sometimes even in special schools:

Now my son's at school, his mother has to go to school every day...waiting outside the classroom...if there's a problem, she deals with it...In fact, it's

just like being chained to the school.

[Jin-seok]

Some teachers [in the special school] are no different from those in the general school...They scolded the mothers, saying things like...‘I’m a teacher. How dare you think that I am here to take your child to the toilet?’...The mothers in this school stay at school...in fact, the mothers can’t complain about such teachers’ attitudes because we worry that if we did, they’d mistreat our children.

[Ji-soo]

The ethos of partnership was perceived as one of the most significant factors in determining the quality of the disabled child’s schooling. The parents firmly believed that, by working together, it would be possible to find some better solutions within the existing resources. However, the wish of many parents to build collaborative relationships with teachers was frequently dismissed through teachers’ lack of respect, unwillingness to listen to the parents’ voices and denial of any responsibility of care for disabled children. This disabling relationship with the teachers was a source of frustration for the parents.

SPATIAL EXCLUSION AND SEGREGATION

The problem of physical access has been widely acknowledged as one of the most disabling barriers that prevent pupils with an impairment from achieving opportunities to participate in curricular and extra-curricular activities in Korean schools (E. Kim et al. 2003). Basic facilities, such as ramps and lifts, which enable

disabled pupils to gain access to buildings, are not provided in most mainstream schools. According to a recent report, 48.8 % of mainstream schools with special classes and 70.9 % of those without special classes do not provide any facility supporting disabled pupils' mobility and access (MEHR 2004).

Given such a poorly designed school environment, disabled pupils encounter high barriers, preventing their access to school resources that are taken for granted by other pupils. Moreover, in order to secure accessibility for their child, the parents have to take on additional care responsibilities. Da-hee, the mother of a son with a mobility problem, described her situation:

Whenever the children have to move class to another one, I have to go to the school. There's no lift in the school...because the music room and computer lab are on the second floor, I have to carry him up and down on my back.

[Da-hee]

However, the disabling environment is not just a matter of physical accessibility. The parents were also concerned that it could impact upon the child's sense of independence and create feelings of isolation. Jin-ho, the father of a son with CP who was a wheelchair user, addressed this problem as follows:

At lunchtime, the other children go out and play together...but my son just stays in the classroom...when I asked about installing a lift in the school, the head teacher's response was 'There are other students and teachers. They can help him to move'...Of course, I appreciate teachers and friends voluntarily helping him to move to other rooms whenever he has to change classes...but it's not enough...They didn't understand that my son needs a lift. He always has to ask someone for help when he wants to go to different floors...if there were a lift, he could go outside whenever he wanted to; he wouldn't have to bother anyone.

[Jin-ho]

The mother of a 9-year-old-daughter with a mobility problem, who participated in a parents' meeting, stressed the importance of an impairment-friendly environment for the child's development of a positive sense of self:

I always carried her on my back to her classroom and when she moved to other rooms [located on different floors] to do science experiments and take music classes...But, this year, she began to feel ashamed about it...one day, my daughter said, 'I'm like a baby. My friends are always looking at me'...She seems to really dislike being shown up in front of other children in this way...If there were a lift she wouldn't feel like that, because she'd be able to move her wheelchair by herself and go around chatting with her friends.

[From field note, 16-03-2004]

Some parents did manage to change the school's physical environment after continual appeals to the school, but this was not an easy task. Rather than recognise that the provision of facilities was essential to meeting the child's basic educational needs, the school authorities usually saw it as a drain on the school funds. Overall, the parents' demands for improved access facilities were frequently diminished as irrational or selfish. Woo-seok's narrative shows this well:

When I asked the principal to install a lift, his first response was 'Are you crazy? Do you think it's rational to totally reconstruct the building just for one pupil?'...I challenged him; I assured him that 'Why it is crazy to do something for a child who really needs it? I know there are some schools that have installed a lift for disabled children.'...He said, 'So why don't you go to one of those schools?'...What made me angry was the way he put the school's problem down to me...He even said to me 'If a lift is so important to your child, you shouldn't have sent him to this school'...When I heard him talk like that, I promised myself I would never give up. I was

determined to change his attitude no matter how long it might take...it took two years for the school to install a lift...but I can't tell you how stressful it was...in fact, I thought several times it would be better to give up...I had to fight so hard with the principal. I went several times to the LEA to complain about it... I even sent a letter to the local newspaper to put pressure on the school.

[Woo-seok]

The spatial exclusion or segregation that disabled children experienced at school was not due merely to the poorly designed buildings. The school's deliberate manipulation of the child's access to facilities and its drawing of boundaries constituted another mechanism by which disabled pupils were segregated from the other pupils, as the following example illustrates:

The special class makes it difficult for our child to contact her other [non-disabled] peers...I heard that, in other schools, children like my daughter join in with the general classes...but the head teacher of my school insists that our children stay only in the special classroom. Because this is separated from the main building, our children can't see the other children, and can't contact them...even at lunchtime, the head teacher forced the disabled children to eat in the special classroom...the school refectory is only used by non-disabled children.

[Source: ADPER, 2004]

This narrative shows that some schools utilise their special classroom as a means of segregation rather than as a resource for promoting the child's inclusion. This further restricts disabled children's access to the majority of the school space and places them in a separate ghetto.

A significant number of parents reported that the special classroom was not only located separately but also placed at some distance from the main buildings,

where the non-disabled pupils spent most of their time. From the parents' perspective, the location of the special classroom was a very important issue because it hindered their children's daily contact with non-disabled pupils and deprived them of any opportunity to socialise with the other pupils. The mother of a son with behavioural problems, whom I met when visiting a parents' organisation, commented:

What mothers expect from schooling is...we hope our children will mix with non-disabled children as much as possible...but the school doesn't help at all...in fact it deprives them of that opportunity...because our children [in a special classroom] are in a different building, there's not much opportunity to contact other children...The teachers might see this as trivial...but, to children like my son, spending time with non-disabled children is very important...to see other children's behaviour is important...The mothers have asked several times for the special classroom to be moved into the building where the other children are studying...but the principal didn't agree.

[From field note: 22-01-2004]

In addition to the physical distance from the general classrooms, the poor condition of the special classrooms contributed to the stigmatisation of the disabled pupils:

There's a joke we mothers tell...if you're looking for the special classroom, the easiest way is to search for the most horrible looking one...it's a joke but it's also the reality...in fact, in many schools, the special classroom that our children use isn't an ordinary classroom...most schools use a modified storehouse...At first, the school kept insisting 'There's no extra room in the [main] building'...we replied 'Build a new one next to the main building, or else give one of the drawing rooms to the special class'...Of course, we wanted our children to be educated in better accommodation...but there was another reason we mothers made our demand so strongly...the other children jeered at our children calling them 'storehouse beggars'.

[Tae-hee]

Tae-hee's story shows another dimension of spatial discrimination and parental practice. As she underlines, the school's allocation of the special classroom was not simply a matter of available facilities. It contributed to producing and reproducing a 'symbolic boundary' between disabled and non-disabled pupils (Armstrong 1999). Because of this, the poor condition of the special classroom encouraged non-disabled pupils to label their disabled peers as an inferior group. Thus, the parents' fight against the school's discriminatory attitude towards the special classroom was necessary for the creation of a school environment that might lead, if not to close friendships, at least to a better understanding of disabled children.

THE DEPRIVATION OF EDUCATIONAL OPPORTUNITIES

One of most common parents' complains focused on the deprivation of appropriate educational opportunities and the neglect of the child's needs, whether in special schools or mainstream schools.

The parents who sent their children to special schools commonly expected that the child would receive more relevant educational services than in mainstream schools. They expected that the teachers would have more talent sensitivity and professional knowledge about their child's potential development and preparation for adult life. However, their expectations and the reality were highly discrepant:

It's a special school in name only...the curriculum is no different from the general school...we mothers asked many times for the curriculum to be

changed to suit our children's needs, but there was no change...After two years' struggle, a new curriculum was finally put in place...We, mothers expect that our children should receive 'real special' education.

[Ji-soo]

The general impression created by parents whose child was enrolled in a special school was that the school offered little more than a childminding service and was devoid of stimulus. Jeong-hee explained why she transferred her son to a mainstream school:

There was no interaction...One teacher takes the class by himself...‘What’s this?’...‘A strawberry’...‘That’s right’...only two or three students were interacting with the teacher...the others were just sitting there...there are no educational advantages...but, if my son went to a mainstream school, he could learn a lot from non-disabled children... at least they’d interact.

[Jeong-hee]

Some of the parents were highly critical of special schools. They pointed to the narrow curriculum and the lack of academic progress made by their children. Some of these parents felt that their children were not given the opportunity to reach their potential. The special school often acts to confine disabled students to the ‘expected limitation’, closing the door to the opportunity to learn because they are not expected to succeed. Mi-seon was very angry about this:

They made our child stupid. There are no classes for mathematics, music, art...half of the classes were just killing time...When my child was in there, he never heard a piano...if there’s an exam, they fix it and report to the LEA...before the day of the exam, the teachers reveal all the answers...They’ve destroyed the minimal hope my son had...they made him more and more retarded...I had to hire a private tutor to teach him...I thought he had the potential to go to university...I asked several times if he

could sit a trial examination...but they didn't even consider it...I obtained it by personal effort.

[Mi-seon]

The poor quality of educational provision in special schools often made the parents to internalise the low expectations of their disabled child. Mi-jeong's narrative illustrates this well:

When she was in the second grade in middle school, I transferred her to a mainstream school...when she'd been there for a while, I was able to see her potential ability...I'd never recognised it before...In the special school, she didn't take ordinary classes...to speak frankly, I only saw her ability as it was limited by the special school programme...she had lots of ability...I was really ashamed...I regret so much that I didn't send her straight from the primary school .

[Mi-jeong]

Mi-jeong's daughter had mobility and communication problems and had been diagnosed with cerebral palsy. At the time of the interview, her daughter was enrolled in a high school. Because of the teacher's maltreatment, she moved her daughter to a mainstream school. It was while her daughter was at the mainstream school that she recognised her daughter's hidden, potential ability. Her experience shows how special schools can eradicate the potential capacity of the disabled child.

According to a policy statement, special classes in mainstream schools were introduced to support disabled pupils' inclusion and to provide a resource room in which the child's special educational needs would be met. However, this support is often non-existent:

Please change the teacher! My child is currently enrolled in * * * elementary school. Because there's a special class in the school, I placed him there. But, the teacher in the special class has no certificate and is just an ordinary member of staff...he is staying to score extra points...The children are currently doing two hours in the morning, but all they do is watch videos, while...the teacher is off doing ordinary school work...I was going to complain about this several times; but I was very concerned that he would maltreat my child.

[Source: ADPER 2004]

This narrative was given by a mother belonging to a parents' association and shows the hidden reality of the special class. Besides the very poor quality of educational provision, it was utilised as a tool for the general teacher to gain promotion.

In addition to the lack of opportunity to receive appropriate educational provision, many parents of children in mainstream schools reported that their child had been excluded from participating in ordinary school activities. Da-sol commented:

Our children have never gone with the other children to do outdoor school activities, camping, or on school trips. We believe that...because our children [in the special class] are also [mainstream] school students, it's right that they should enjoy happy times playing and participating in school activities with other children...but the teachers always said... 'We can't take them along because there could be an accident'...they only see our children as a burden...Of course, our children might cause some trouble and they'd need more attention...but, if the teachers made an effort, our children could go...We mothers suggested, 'Some of us will go with them'...a special teacher also volunteered to go...but the teachers said 'No'...and kept on just repeating 'Each mother will have to go and take care of her child, otherwise we can't take them'...they don't want to be bothered by our children...

[Da-sol]

FACILITATING THE CHILD'S FRIENDSHIPS

Given the unfriendly school environment for disabled children, the parents' involvement in their child's schooling was somewhat different from that of others without disabled child. Many parents, whose disabled child was placed in a mainstream school, felt that they needed to fulfil additional roles in order to mediate the relationships between their child and his/her non-disabled peers. The parents, especially those in the ordinary classroom, considered it important to handle the other children's feelings of fear, uncertainty or negativity which might be aroused during the initial contact with their child's different appearance or behaviour. Interestingly, a significant number of parents employed similar tactics – what they called 'give me the first class'. Dong-keon, the father of a son with a cognitive impairment described his own actions as follows:

First impressions are very important! I always ask the [home] teachers to give me the first class when the new school year begins so that I can talk about my child to his classmates...I used to say things like...'Your friend has an impairment but he's the same as you. If you try to understand him a little bit, he'll be your friend. If you give a little help, he can take part in school life as much as you can. But if you reject him, he'll have to go home. Do you want to study with him here or send him home?'...In such ways, I try and persuade them...kids are more likely to accept our child than adults are...most of them say, very seriously, 'I like him studying here'.

[Dong-keon]

Dong-keon strongly believed that reducing other children's prejudice towards his child's impairment was the precondition for forming positive relationships between

them. As well as giving the other children information about his child's impairment, by invoking their moral sensibility, he tried to encourage the other children to accept his child as a member of his peer group and promote a sense of sameness and togetherness.

In order to secure their child's positive relationships with non-disabled pupils, some of the parents felt that it was important to have a similar engagement with the parents of non-disabled children. Eun-kyeong, the mother of a son with autism, recounted:

In the first year [of primary school], I just thought a good relationship with the teacher was enough but it wasn't. How the other parents [of non-disabled children in the class] think of Min-hyeong [her son] was also an important thing...I heard that one disabled child, who had entered the school [which her son was attending] a year earlier, had had to move to a special school because the other parents very much disliked the idea of their children studying with the disabled child in the same class...Children like my son usually get a lot of stress at the beginning of the new school year. They often shout out suddenly, and walk here and there because they can't adapt themselves easily to a new environment and new faces...I thought...the children in the class would talk about Min-hyeong to their parents at home and the parents would only see my son as a problem hindering their children's study...I was concerned too...the parents would say to their children 'Don't play with him'...thinking my son was dangerous...So I decided to show my son to other parents and explain directly his behaviour and ask for their understanding...I brought him with me to the first general meeting of parents...There were some parents who really appreciated that my son would learn a lot of things when he's with other children...they gave me lots of encouragement...and there were such thoughts too...there would be one or two mothers at least saying to their children 'You have to help Min-hyeong' and 'Tell other children not to do bad things to Min-hyeong'...so I always tried to participate whenever there was a parents' meeting and talk about my son.

[Did it really work as you expected?]

Yes, it worked...he's made some good friends. They're coming and playing together at home now...their mothers sometimes called and came over to our house to see my son.

[Eun-kyeong]

As this story vividly shows, Eun-kyeong's involvement in encouraging her child's relationships with non-disabled pupils extended to reaching out to their parents as well. What she intended was not simply to mitigate the other parents' potential criticism of her child's impact upon their children; she was also very concerned that prejudice towards her disabled child from other non-disabled families might act as a significant barrier to developing the child's relationships with her non-disabled peers. As she explained her concerns, other parents' negative perception of her daughter could be transferred to their children's understanding of her child, and, as a result, prevent her from making friends and integrating with her peer group. So, for Eun-kyeong, socialising with other parents – through instilling a realistic understanding of her child's impairment and conveying a positive sense of a disabled child to them – was an important task in securing her child's 'participatory socialisation' (Turnbull, Pereira and Blue-Banning 1999).

For many parents, 'explanatory work' was a part of their involvement in their child's day-to-day schooling (Read 2000). The parents tended to see other children's naïve curiosity about their child's impairment as a positive sign that they would be supportive. By giving full explanations to the questions that the curious, non-disabled pupils raised in their day-to-day interaction with the disabled child, the parents contributed to reducing their feelings of strangeness or distance. Ka-yeon's story illustrates this well:

When the new school year began, I asked the teacher to allow me to use the Internet Café [class homepage]...After a while, I sent a letter about my son

to his classmates. Many of them began to ask me lots of questions about my son's impairment like... 'Why did Dong-il become ill?', 'Why does he laugh all the time?', 'What can he do by himself?', and so on... As far as I could, I tried to give a full answer... explaining about his behaviour in detail, because it would help them to understand my son a bit more positively... They often told me stories of what had happened in school... 'Dong-il was so noisy and walked around in class lots of times today', 'Dong-il went to the playground at break time and didn't come back, so I brought him with me to the classroom'... I replied to the child, 'I'm happy to hear you did a good deed'... 'Dong-il touched Sua's face today, so she cried'... I explained, 'Dong-il likes soft things. I think he wanted to say he liked Sua. He doesn't mean to annoy her'... Exchanging e-mails with the other children was really helpful to me... I hear about my son's school life from them. Above all, it's good to know what the other pupils think about my son... they seem to have learnt what Dong-il likes and dislikes.

[Ka-yeon]

Everyday contact can more effectively reduce the other children's misunderstandings or negative images of the disabled child than casual attempts at explanation. By using the Internet as well as casual social contact with the children, Ka-yeon tried to disseminate more accurate information and detailed knowledge about her son's specific impairment to his classmates, and to present her son in a more positive light. From her perspective, the strategy of encouraging the children to achieve a deeper understanding of her son's strengths and needs contributed a friendlier and more supportive environment.

Despite the fact that their motivations are driven primarily by their protective instinct and also by a desire to establish their child's participatory socialisation, it should also be noted that the parents' undertaking of mediatory roles in their child's relationships with his/her non-disabled peers was an important means of creating a disability-friendly culture within the school environment.

CONCLUSION

This chapter has explored the parents' involvement and experiences in the school setting. For the majority of parents, the school was a site in which they witnessed, experienced and struggled with disablement. Disabling values are deep-seated in schools and lead to direct dehumanisation of the disabled children by both the administration and the teachers. Many of the parents also reported that their child was excluded from ordinary school activities and denied educational opportunities because of the lack of support. In spite of this harsh environment, most parents were seeking better solutions through active involvement in the school. However, their hopes regarding constructive collaboration with the school and the teachers were often frustrated, and their right to act as advocates for their child's needs was not taken seriously and often denied. This chapter also highlighted another significant mediatory task that the parents undertook in the school. A substantial number of parents tried to engage actively in creating healthy, positive relationships between their child and his/her non-disabled peers by facilitating friendships.

The following two chapters discuss the parents' experiences of group work. As explored in previous chapters, the parents have struggled with a number of interlocking problems, ranging from unmet needs for services to the deprivation of their child's opportunities to participate equally in mainstream activities, to direct discrimination. In the process of seeking solutions to the problems they encountered, many parents came into contact with the parents' groups. Some parents actively

sought others' help and recognised the importance of collective power to bring about change. The next chapter will trace the personal pathways through which parents become involved in group activities and examine why and how they come to embrace group work as an important aspect of their parenting.

CHAPTER SEVEN

GETTING INVOLVED IN PARENTS' GROUPS: PERSONAL PATHWAYS AND MOTIVATIONS

INTRODUCTION

As discussed in the previous three chapters, parents of disabled children experience various forms of disablement. However, in this unfavourable social circumstance, parents also try to seek workable solution in their own specific ways and create more a favourable situation for their disabled child. This chapter examines the various motivations that prompt parents to become involved in self-help groups and how their involvement is closely interrelated with their grounded experiences of disablement. In doing so, it also highlights how their engagement in group activities needs to be understood as a way of seeking solutions to the problems they face, and, at the same time, of transforming their parental practices in more collective ways in order to challenge the disabling social forces.

LOOKING FOR ALTERNATIVE RELATIONS

The parents of disabled children are likely to be isolated and estranged from others in a society where a child with an impairment is perceived as 'tragic', and the experience of rearing that disabled child as very different to that of 'normal' family life (Gregory 1991; Landsman 1998). The desire to meet other, like-minded parents who are in the same situation and therefore would understand the practical and emotional difficulties of rearing a disabled child constitutes one of the most significant factors motivating parents to contact and join a parents' self-help group (Darling 1988; Pizzo 1983).

Min-joo was one of the parents who wanted to meet other parents with disabled children. She hoped that she would be able to talk freely and share her experiences of mothering without having negative feelings about herself or her disabled son:

When I met friends, I felt I wasn't really a part of them. You know, what they were saying about their children and how they get on with everyday life was...what can I say?...my life seemed so different from theirs. Although they could sympathise with me, I didn't think they really understood my situation. I sometimes felt that they were uncomfortable talking about their children; they'd noticed my expression after they'd been telling happy stories about their children...Above all, I didn't like listening to what they were saying out my child and me...even though I tried not to think like that, I often found myself comparing my child with their children...I wanted to meet some people who could really understand what it's like to bring up a child like my son...for me, talking with other mothers [of disabled children] was really comfortable.

[Min-joo]

Min-joo repeatedly confirmed that she could not participate in or enjoy her friends'

talk about rearing their children because, she felt, the task of rearing a child without an impairment was fundamentally different from bringing up a child with a cognitive impairment like her son. Even though her friends never showed any negative attitudes towards her son, she frequently found it hard to talk about her difficulties because her friends saw her child only as to be pitied. Min-joo also recognised that talking about mothering experiences with her friend could pose a threat to developing a positive relationship with her son. She was very concerned that the continuous confirmation of 'difference' in her interactions with her friends made her think that her life was unhappy and not 'normal', and she found herself having negative feelings towards her child. As a result, she stopped meeting her friends and instead sought out new types of relationship that would offer her positive insights into effective ways of mothering.

The desire to exchange experiences with other people who are in a similar situation was no different for fathers; indeed, the fathers were especially keen to talk about their concerns and difficulties related to rearing a disabled child. This is because they usually take on a demanding breadwinner role to meet the family's high childcare costs and spend most of their time in the work place, so fathers have more limited opportunities to meet and form relationships with other families with a disabled child. Jin-seok was one such father, who wanted to establish relationships with other fathers in the same situation as himself:

What I felt really good about when I first met other fathers [in the fathers' gathering] was that I didn't really have to disguise myself...I mean, I could say whatever I was thinking without feeling uncomfortable...I didn't hide my child's impairment from other people during the meetings. But, as you know, it's not easy to talk about a child's problem or financial difficulties...to talk about that kind of thing can be seen as...a kind of...lack

of ability on my part...Who would guess that we have to pay as much money as our monthly payment to buy one piece of equipment for our child? Who can even understand that, sometimes, I have to make some excuse not to go out on a big drinking night with friends, lying that my mother-in-law is coming to visit me from another city far away...to enjoy myself even for one day was sometimes a problem for me...if they don't have a disabled child, people can't really understand such things...But when I talked about this kind of thing with other fathers [of impaired children], I realised everybody who came here had the same kinds of problems as I have. We could easily understand each other's stories...We all have similar difficulties and problems.

[Jin-seok]

Jin-seok was running the fathers' monthly gathering for a parents' organisation at the time of the interview. He emphasised several times during the conversation the importance of having a space in which fathers can talk freely about their difficulties and anxieties without worrying about others' negative responses. The shared understandings and feelings of caring relationships he experienced at the fathers' gathering gradually led to his involvement in the parents' group.

The parents of disabled children who are in a difficult relationship with their extended family members often have a strong desire for emotional support and encouragement from others who can understand the difficulties that they face. They may look for a trusting relationship in which their personal problems can be discussed without prejudice to themselves or their family. Ji-weon, among other interviewees, contacted a parents' group in the hope that she would receive more effective support from other parents and thus ease her loneliness:

When I looked at the homepage, I felt that the mothers [in the online community] looked like they were really close. They seemed to know each other's children quite well and about each other's lives too. The replies they wrote to one mother were all so kind and nice...I really envied them having such a relationship with another similar family. I also wanted to become a

friend like them...I don't remember what I wrote exactly but I sent several lines. I'm sure I said something about my problems with my in-laws. Several mothers sent replies to what I'd written and these were so touching...I became closer to those mothers, especially the ones who replied to me at that time. We exchanged emails almost every day, talking about our private problems...After exchanging e-mails for a while, the mothers invited me to one mother's home...Having some time to relax and chat with other mothers was so good for me...the mothers were like older sisters. They understood my difficulties and always took my side...That was the most important reason for me to become involved in this group.

[Ji-weon]

Ji-weon's husband worked for a company located in a different city. Her parents and sisters also lived in another city that was very far from where she lived with her children. Even though her parents-in-law lived in the same city, she had not been able to build a close family relationship with them because they had objected strongly to her marriage to their son. Ji-weon explained that their negative attitudes had been reinforced by the news of their grandson's impairment. Her parents-in-law sometimes even put her husband under severe pressure to get a divorce. Considering that family support plays such an important role in overcoming the parents' emotional difficulties (Thomas 1998), it is not difficult to understand that Ji-weon experienced the impact of having a disabled child in a particularly harsh way. In addition to the antagonistic attitudes of her parents-in-law, her husband's staying away from home made her feel even more lonely. She wanted friends who would help her to cope with her emotional difficulties. By meeting other parents who sympathised with her problems and gave effective care, Ji-weon was revitalised and felt able to overcome her everyday frustrations and feeling of isolation. The family-like support of the other parents helped her to construct trusting relationships with them and encouraged her to work closely with others in the parents' group.

CONTINUING POSITIVE PARENTING

As has been widely documented, accessible information and knowledge are crucial in enabling the parents effectively to meet the disabled child's special needs and also deal with the day-to-day issues that arise while rearing the child (Beresford et al. 1996; Read and Clements 2001). If the necessary information and knowledge are not easily gained, the parents have to invest substantial efforts of their own, which increases the difficulties associated with raising a disabled child. For many of the parents in this study, their repeated experience of difficulties in trying to obtain useful information and the lack of support from the social services were significant factors driving them to join parents' groups. Yun-ji is an example of a mother who joined a parents' group to acquire more knowledge about how to bring up her disabled child:

When I heard the news that some parents had got together and set up a parents' association in this city, I didn't hesitate to join it...It was at a very early stage and we had no offices...Although it wasn't yet properly organised, I was really glad that over a hundred parents could get together...I could see all kinds there, from those with a young child to those with a disabled adult son or daughter...I heard a lot of stories about schooling in middle and high schools and learnt a lot...In rearing my child, the most difficult thing was to get information. It was very hard and stressful to search for all kinds of information by myself...It was so good for the mothers to get together. Honestly, what I heard from the other mothers, they were a lot more helpful than what I gathered by myself in over a month.

[Yun-ji]

Yun-ji, like other parents, emphasised that, in the process of rearing her disabled child she always put an enormous amount of time and energy into getting any significant information on services for her child's development. In particular, when facing critical moments, such as sending her child to school, a great deal of new

knowledge, understanding and information had to be sought out and accessed by herself at the cost of a high level of stress. However, at the parents' gathering, she was able to obtain more helpful knowledge than she had gathered by herself. In particular, listening to the older parents' stories, which gave her some idea of what she would experience later, she saw as an important benefit, enabling her to become a more competent parent. She firmly believed that sharing knowledge and childrearing experiences among parents was a powerful antidote to the frustration and anxiety that was prone to occur in their lives. Yun-ji's experience of receiving valuable information and advice from other parents at the gathering made her appreciate the importance of the parents' group and also led her to undertake a voluntary role, counselling the mothers of younger disabled children.

Je-ook was another parent who experienced severe difficulty in accessing information at critical times. Like Yun-ji, Je-ook valued his parents' group as a centre for knowledge gathering. He wanted to know what to do and how to move forward to procure the best possible future for his daughter by listening to and learning from the experiences of other parents:

Since she went to primary school, the time has passed swiftly...one day, my daughter began her menstruation...how can I explain the shock I had...the shock was as strong as the time I first knew she had an impairment...It was clear that she would become an adult... but, really, I had no idea about how to live with my daughter...Do I have to teach her something about sex? Could she marry someone? Does she have to stay at home after leaving school?...you know, a lot of questions were knocking around in my head, but I didn't have any ideas and just couldn't picture her adult life. There was nobody to talk to about this. I'd only seen children of my daughter's age. Even in places like SWC [Social Welfare Centre], I couldn't see any adult children with an 'intellectual impairment'...I looked around here and there...and I learnt about this [parents'] association, and, through it, I met several parents of adult children and I did get a lot of help from them.

[Je-ook]

Je-ook's daughter's onset of menstruation forced him to consider her future life and to rethink his parental role. Facing the fact that his daughter was in transition to young adulthood, he wanted to get some idea of what her life would be like and what he had to do to prepare for her future. However, as he mentioned, there was no available source that would help him to make sense of his future parental roles. In part, his lack of information and knowledge about disabled adults' lives reflected the dominant pattern of Korean social service provision for disabled families, which has been exclusively focused on the rehabilitation of young children (Y. Kim and D. Yu 1999). He had actively to seek information in order to overcome this deficit and to provide some guidelines that would enable him to continue his parenting in a positive way. This led him to contact the parents' association, which had a network of parents of younger disabled adults.

For some of the participants, participation in the parents' group was valued as a way of facilitating positive parenting in terms of balancing the care of the individual and of their child. Rather than conceiving it as an extra burden, this group of parents, particularly mothers, saw undertaking certain voluntary roles in the parents' group as a source of revitalisation and a way of regaining their self-esteem.

Mi-jeong commented:

I had to put in extra time doing things for this group...but to speak frankly, the primary reason I'm doing something here...this is my social life...Even though caring for my daughter is my task and natural duty, I have my own life to live too. I hoped it would do something for me...It seemed that it was a kind of negotiation...when I spent a whole day with my child, I couldn't help thinking in a way 'What am I doing now? What is my life?'...I felt depressed so many times and I sometimes treated my child irrationally...Doing this group work, I felt, I became free from bad feelings

about myself...giving counselling and some help to new mothers gives me some energy, you know, a resource for treating my daughter better...I couldn't make money there, but, in many ways, it helps me feel alive and do something for my development. If I didn't have a disabled child, I wouldn't have known how very difficult it is to bring up such a child...Doing something for our children and their mothers is very important and valuable to me...now I really think this work is another way of living life.

[Mi-jeong]

Like other mothers, Mi-jeong was a primary carer and had very limited opportunities to participate in social activities. It seems that her engagement in the self-help group was motivated by her desire to overcome her feeling that her life was meaningless. Her participation in the group provided the opportunity to increase her sense of self-worth in that she appreciated undertaking certain voluntary tasks for other disabled families as a way of developing a new career and forging a new life style. At the same time, as she underlines, her participation in the parents' group work enabled her to continue positive parenting without feeling self-indulgent.

THE NEED FOR COLLECTIVE ADVOCACY

Disabled children have often been deprived of equal chances to participate in mainstream social activities and they are often exposed to various forms of discriminatory treatment in the public sphere (KWSS 2002). As discussed in previous chapters, the parents undertook mediating roles to obtain their child's inclusion and sometimes conducted assertive advocacy in order to protect the child from unsafe situations. However, in dealing with institutional power, they often encountered disabling barriers when raising their voices to secure his or her children's

welfare and rights. In the process of searching for others' help to solve these problems that they encountered, some of the parents contacted parents' groups and came to realise that group power would be a most efficient tool by which to bring about change.

Ji-min, for example, acknowledged the importance of parents' group advocacy in the struggle for her child's inclusion in mainstream social activities:

I don't remember who first mentioned it, but one mother among us suggested asking the cultural centre and gymnasium [run by the city council] to set up a programme that our children could join. There were six of us mothers; we went there many times to ask for it, but they didn't take our demands seriously. They kept saying things like 'There are other gymnasiums specially for disabled people that offer special programmes for disabled children. If you want that kind of programme, go there'...We knew that there was one for disabled people...but to get there and back would take over two hours...As far as we are concerned...we pay tax to the city council too and the institutions are actually run with our money. So why couldn't we use it?... Anyway, once we'd started, we couldn't stop...it's true we had no power...we thought they treated our demands in that way because there were so few of us...In the process, we got to know that there was a parents' association. We were talking about this issue with one of the leaders of the association, and she said 'Let's ask for this under the name of the parents' association. We have at least a hundred parents and we can get their signatures'...At that time, I thought that if we really wanted to do something for our children, it might be better to act together with other parents...when we act individually, people in these kind of institutions treat our demands as trivial, you know, like a personal complaint, but when we brought the collection of parents' signatures, they changed their attitude towards us.

[Ji-min]

Before getting involved in the parents' group, Ji-min had been friendly with a few mothers whose children had a similar impairment. Following one mother's suggestion during the informal gathering, she and the other mothers requested that the sports institutions run by the city council should offer a programme suitable for their children. Rather than simply meeting their children's individual needs, the mothers' intention was to change the traditional way of thinking; that disabled

children cannot use the same facilities as non-disabled people. However, in the process of dealing with the institutions, the mothers felt that their voices were not being taken seriously. Through their repeated attempts and failures, they came to realise that their efforts could not succeed without collective power and contacted the locally-based parents' association. The group's advocacy enabled the mothers to change the attitude of the institutions and set up new programmes in which their children could enjoy leisure activities with their non-disabled peers. This experience gave Ji-min a strong belief that the needs and rights of disabled children could effectively be achieved through parents' collective power and led her to become deeply engaged in the group's activities.

Yun-seo recounted how her own experiences of direct discrimination led her to participate actively in the parents' group. Like other parents, she wanted her son to enjoy school life in an inclusive educational environment. However, from the first year of her son's schooling, she experienced negative attitudes on the part of the teachers' towards him, so much so that she often felt that she was under pressure to transfer him to a special school. Despite her continual efforts, the school authority made no attempt to improve the school environment so that it would be more supportive of disabled children. Moreover, the school deprived the children of the opportunity to be educated equally with non-disabled pupils and even treated them in a dehumanising way:

The class teachers made a joint decision, without notifying us, that they would allow our children to stay in their classes for only two hours. But, at that time, there was no class that admitted our children. They forced our children into the old library which had been closed quite a long time ago... you know...it was like a storehouse...filled with recyclable waste, dirty books and covered with mould...even the heating system wasn't working.

The children are all precious sons and daughters in their homes... being treated like that made us very angry...but at that time, I didn't know what to do about it...I and the other mothers [of disabled children] sent letters to the head teacher several times to get his sympathy but the school just kept on ignoring us...the only place we knew at that time was the RIDAPR [Research Institute for the Differently Abled Person's Rights]. We went there and consulted with the staff about the problem. They told us that they'd help us if we couldn't persuade the head teacher. Once we got that kind of support from them we were able to confront the school...Anyway, the school agreed later to build a new classroom for the children and, until the classroom was ready, the children would stay in their [regular] classes. If there hadn't been an organisation like the Institute, I couldn't have fought against the school so strongly.

[Yun-seo]

The school's obvious discrimination against disabled children and its denial of the parents' appeals for improvements in conditions for their children prompted the mothers to choose direct confrontation with the school authority. However, the mothers became aware that their personal efforts were not strong enough to bring about changes and they therefore sought help from others. Yun-seo's contact with an advocacy organisation and getting encouragement from its staff was a significant experience, which convinced her of the importance of collective advocacy. Yun-seo came to believe firmly that, when parents face unfair treatment, such allies are a most powerful resource in enabling parents to gain a sense of empowerment and thus to fight against any deprivation of their children's rights. This experience gave her a strong motivation to meet and build networks with parents of disabled children enrolled in mainstream schools in the region where she lived. Over time, she took a leading role in forming a locally-based parents' association for inclusive education.

Da-sol also recounted that she had become involved in parents' group activities in the process of struggling with her child's exclusion from school activities and seeking a solution. As mentioned in chapter six, the disabled children in the

school at which her child was enrolled could not participate in ordinary school activities, such as school trips and even one-day school excursions. In order to appeal against this discrimination, Da-sol and other mothers of disabled children went to the LEA (Local Education Authority), but the LEA staff did not treat their complaints seriously and were reluctant to intervene, arguing that the decision was a matter for the school and, therefore, the problem should be solved through improving relations between the school and the parents. Because the LEA's proposed solution was unacceptable, they decided to find out if the children in other schools were in the same situation and if so, what the parents had done about this problem:

...After a while, we learnt that the mothers of children in middle and high schools had a kind of network...At about this time, we got a phone call from one mother who had a son attending a middle school. She said that the mothers were pressing the LEA to establish more special classes in [mainstream] high schools because there were only two running special classes in this region, and that they needed other mothers' help...As soon as I got the call, I was sure that there was a good chance we'd solve the problems we had in our school because those problems couldn't be solved on a school-by-school basis. After I talked with the mothers [in my child's school], we decided that we should do something together with the other mothers [who were asking for our help] and so make a common issue of the problems we all have...Because at that time there was no formal association of mothers in this region, we decided to form one and fight together, first to increase the number of special classes and then to solve our problems. That was the starting point for this parents' association.

[Da-sol]

Like Yun-seo, the deprivation of her child's educational opportunities and unfair treatment at school was a strong motive for Da-sol to participate in group activities. For Da-sol, who was looking for solutions, meeting parents who were experiencing similar problems was valuable because it provided a possible way of solving the problem that she was encountering in her struggle with the school. She realised that it

would be more effective to combine the parents' individual efforts and act collectively in order to influence the institution's practices.

Many parents in the present study reported that their engagement in parents' groups was strongly motivated by their personal experiences of discrimination or by a sense of personal injustice and an awareness that they were being neglected by their child's rights by the existing institutional practices. In the course of struggling with changing situations, they came to believe that their problems could not be solved by their own individual efforts alone and that the development of the parents' collective power was essential to bring about the desired changes.

WITNESSING 'ACTIVIST PARENTING'

The opportunity to experience a new form of parental life is another factor motivating parents to participate in group activities. Witnessing other parents' assertive actions towards changing disabling conditions, they experience a critical moment in which they redefine their parental roles and responsibilities.

Woo-seok was inspired by what the parents' assertive actions had achieved in another country. He was a priest and a founder member of APCCP (Association of Parents of Children with Cerebral Palsy). When he talked about his engagement in parents' group activities, Woo-seok identified his trip to Australia as a significant moment:

I had the chance to visit Australia with some other priests to study the welfare system and services for disabled people. It was a ten-day visit and it

was actually the first time I'd travelled with my wife after our disabled child was born. When I looked at the welfare system, services and institutions, I thought they were really fantastic; not at all comparable to those in Korea. Above all, the most valuable thing that I got from the trip was that it opened up my eyes and mind...I came to have a 'real vision' of what I could do for my child...There was an organisation called Q.A...an organisation of people with severe spinal injury. I met a woman in her fifties there...I told her honestly 'I'm really impressed by your country's service system for disabled people'. When I asked her how it had been developed so well, she said 'It's all due to the struggle of the older generation of parents for their disabled children over 40 years. It's the fruit of their long fight, of their tears. We're now tasting that sweet fruit'...What she said was a great inspiration to me at that time. It made me think 'I'm the parent of a disabled child too!' and 'What does Korea look like in comparison!'...[In Korea] parents are almost invisible and they don't have a voice. So I thought that I would live as a 'real' parent, as the parent of a disabled child. I thought I had to do what Australian parents had done in the past.

[Woo-seok]

The original purpose of the trip was to get some idea of the institutional services and programmes for disabled people, which might be the model within the Christian community to which he belongs. However, by meeting and talking with disabled people working in self-help organisations, Woo-seok learnt that the considerable progress in the welfare system for disabled people in Australia had been achieved through a long struggle for disabled people's rights. He was particularly inspired by the fact that the parents' movement had been essential in changing governmental policies and bringing about a great improvement in disabled people's lives. This awareness of the importance of collective action in the success of the parents' movement led him to redefine his parental roles in more social and political terms. He went on to play a leading role in the mobilisation of parents and continued his commitment to the group's development.

Jeong-eun was another interviewee who was strongly motivated by parents' actions. Her recognition of the potential of parents' collective power directly inspired

her to become engaged in working with other parents:

One day, I got a call from a mother who was also one of the mothers involved in the same SWC. She suggested that I pop into a parents' meeting. She actually asked me to go there on her behalf because she had something to sort out urgently. So I did that...It was a big meeting. Many parents were there...They presented their experiences of, how they were discriminated against in the school and how their children were treated. They strongly criticised the schools and teachers...I was really impressed because they were so different from the mothers I met every day in the school or SWC...Seeing them talking about their problems in that critical way, not just lamenting their fate, I thought to myself 'Aha, parents can talk about what they've experience in a quite different way. Parents can talk to each other in this way when they get together'...I thought I was hearing 'real voices'...Because I'd some similar experiences, I raised my hand and told my stories about school...when the meeting was over, several mothers came to me and asked for my telephone number, saying that they wanted to talk with me about their own problems...Other mothers asked me to help them because they thought they were experiencing what I had gone through.

[Jeong-eun]

The parents' meeting was arranged to report cases of discrimination in schools and to promote networks of parents in mainstream schools. It was the first time that Jeong-eun had seen a large number of parents gathered together, raising their voices to articulate their collective experience. As mentioned in chapter six, she had experienced the teachers' continual maltreatment of her child and occasional verbal attacks on him. Faced with such discrimination, she had felt compelled to transfer her son to a special school. Listening to other parents' stories of school discrimination, she felt a sense of comradeship with them. Furthermore, her direct impression of the parents' meeting provided a crucial moment in which she was able to gain an empowering sense of belonging to a group. She identified this experience as an important life event, which led her to engage in group working as a part of her daily parenting activities.

Tae-hee's story provided another example of the parents' involvement in group actions. She recounted how the impression she received through participation in direct action caused her to reflect on her views about parental roles:

I knew that some mothers were working very hard to resolve their disabled children's educational problems. Even though I respected their efforts, I didn't think I could be like them...I was just a housewife...To be honest, I only thought about my family and bringing my child up well...It seems that the day really changed me...I can still remember; it was raining when the parents had a demonstration in front of the LEA building...about a hundred parents were sitting on the ground without umbrellas. They were already soaked, but nobody left and everyone was shouting and raising their hands...Some mothers had brought their children and the children were sitting beside their mothers, holding little umbrellas. When I saw that scene, something hot seemed to well up from the bottom of my heart...I couldn't stop tears running down my face...I thought, those mothers are sitting there and fighting for children like my son. I was ashamed of myself...I asked myself 'What have I done and what am I doing here? Why aren't I fighting like them? Why not do what those mothers are doing?'

[Tae-hee]

It seems that Tae-hee considered disability-related problems as family issues and her efforts had been restricted to the family context. She said that she had naïvely believed that activist parents were different to her and had never thought about working towards changing the social situation. For her, being deeply impressed by the parents' direct political action was a critical transitional moment in which she rethought her own roles and responsibilities as the parent of a disabled child. During the interview, she emphasised several times that this experience was an important turning point in her life in the sense that she went on to develop a new career as an activist parent.

CRITICAL THOUGHTS ON THE CONVENTIONAL DISABILITY ORGANISATIONS

As discussed above, for many parents, their engagement in parents' groups entailed a process of transforming their personal practices into part of a consciously collective struggle against the disabling social forces and redefining their parental roles within a social context. However, some of the parents explained that their commitment to group activities was also prompted by their critical interpretation of the problems connected with the pre-existing parents' or support organisations. Amongst others, Dong-keon clearly identified his reason for becoming involved in a parents' organisation: he wanted to develop it so that it would be more political and act as a pressure group for demanding the disabled child's rights:

I'd been involved in the civil rights movement for a long time...but, after I realised that my son would have to live with an impairment, my concern moved to what I could do for him...Since I'd become an interested in disabled children's issues, I recognised that there were so many problems with the education and service provision for our children...I thought it would be better for me to work for disabled children and their families, and I met a lot of people in the parents' groups...When I looked at the other parents' groups, I saw that the parents hadn't often been able to get our children's problems on to the social and political agenda. I know that, because of the burden of caring for their children and financial difficulties, parents don't have much time to go in for political campaigning. But the real problem is that parents don't approach disability problems in terms of changing the social system.

[Dong-keon]

The parents who have prior experience of participating in a certain form of social movement probably feel strongly the need for the politicisation of parents' groups and are more likely to become involved in disability rights politics. Dong-keon had

been working as a leader of a branch of a national civil rights movement organisation before having a disabled child, so his prior experience of political activism strongly influenced his view of disability problems. As his narrative indicates, he firmly believed that the difficulties faced by disabled children and their families could be solved only by bringing about change in the social system. In the course of contacting many parents' groups, he realised that they had remained apolitical and lacked the capacity to make disability a social issue and to mobilise the parents of disabled children. This realisation prompted him to embark on a new career in the parents' disability movement and commit himself to politicising the existing parents' groups. After a relatively short period of participation, compared to other parent activists, he began to play a leading role in mobilising the parents' groups and initiating a variety of political demonstrations in his region.

Some of the parents interviewed reported that their deep engagement in parents' group activities was prompted by their critical evaluation of the problems of the conventional disability organisations and the acknowledgement of the necessity for developing a parents' group that firmly advocated the rights of disabled children and their families. Dae-whan was one of the parents who were actively engaged in forming a parents' association in opposition to the existing organisation run by professionals. He was one of the older participants in the study. At the time of the interview, his son, who had an intellectual impairment, was 28 and worked in a small sheltered workshop, which Dae-whan had established with other parents of adult disabled children. When his son graduated from high school, Dae-whan sent him to an institution, but, after a while, took him away again because he had been very unhappy there. While looking for ways to help his son prepare for his adult life, Dae-

whan contacted an organisation established to support people with an intellectual impairment in order to enrol his son on the vocational training programme it provided. However, Dae-whan emphasised that what was particularly beneficial to him was that he began to form close relationships with other parents of adults with the same impairment as his son. At the time that he became an active member of the organisation, the exclusion of people with an intellectual impairment from newly implemented national welfare policy was a great concern to some of the parents in the organisation. These parents, including Dae-whan, decided to appeal to the government to extend the application of welfare benefits to those with an intellectual impairment. The parents expected that the leaders of the organisation would support their decision. However, the leaders were antagonistic towards their struggle to amend the governmental policy:

Some parents said that an appeal should be made to the national government, and so we brought this issue directly to the leaders' meeting. But they said to us, 'Don't even mention the initials of this organisation; if you want to do it, do it by yourself'...I got the impression that they didn't want to create any trouble for the government...Anyway, we went to the members of the National Assembly several times...and, after one year's campaigning, we finally obtained a tax reduction on purchasing a car, to be applied to people with an intellectual impairment and their families...But, at the bi-annual members' meeting, the head said it had been granted because of the organisation's appeal...We complained: 'This organisation hasn't contributed anything to the result. The leaders actually opposed our campaign'...but, because there were so few of us, we were forced to leave the room...Because of that experience, we realised we'd have to build an organisation run by the parents themselves...The people in the organisation weren't really on the parents' side. They were only interested in their reputation and maintaining the organisation as it was.

[Dae-whan]

Considering that the organisation was supposed to represent everyone with an intellectual impairment, it should have supported all kinds of struggles in the

interests of that population. However, the organisation did not provide any help for the parents' action to revise the governmental policy that directly affected the welfare of people with intellectual impairments. Moreover, the organisation stole the parents' achievement. It seems obvious that the leaders of the organisation were concerned only with its interests and sustaining its formal reputation. Witnessing the organisation's distorted way of operating, Dae-whan realised that it was necessary to set up a new parents' group which could truly reflect the parents' voices, and to secure the members' participation in all of the groups' activities.

Mi-seon also explained that she had become deeply committed to group activities as a result of experiencing adverse reactions from conservative, overly bureaucratised disability organisations. Like other parents, Mi-seon's engagement in parents' collective action was initially prompted by her struggle to secure disabled children's needs at the school. Before the parents' action began, the school foundation decided to dispose of the school's land and move it to another building, which was very old and also a long distance from the original location. Even though it was a special school, where pupils with severe physical impairments were enrolled, the building that the foundation had arranged to purchase had not been designed to accommodate such pupils or be accessible to them, and also lacked the necessary facilities. The parents strongly opposed the school's decision to move into the new building and tried to persuade the foundation to reverse their decision. Despite the parents' efforts, the move went ahead and the parents began to protest against the school authorities. After a year-long campaign, the parents succeeded in forcing the school foundation to withdraw its planned scheme and made the LEA allot a special budget to improve the school's physical accessibility. However, in the process of

fighting against the school authorities, they encountered many difficulties and desperately needed support from other groups:

...We felt it was going to be very difficult for us mothers alone to beat them [the school and the LEA]. We desperately needed the help of others...At that time, there were two [disability] organisations...in order to pressurise the school, we thought it would be better to fight together with the people there...so I and some mothers went there to ask for their help...they just told us not to go to that extreme with the school and they tried to avoid joining us. The leaders of the organisations didn't take the problem seriously at all...it seemed that they were afraid they wouldn't get support from the local government or the city council any more, if they got involved in this kind of fight...all they were worried about was how to maintain their organisations without getting into any trouble...the organisations even persuaded us, saying that going against the LEA is never a very good idea, never benefits the parents...the groups that helped us were other civil rights organisations. They gave us the know-how to make issues public effectively and really supported us...Why I continue this (parent) group comes from that experience. Of course, this group is very small and we don't have the resource to provide services as much as other (existing) organisations...but what is really helpful for parents is to advocate for them and to fight together with them when they are in the difficult situation.

[Mi-seon]

Mi-seon expected that the disability organisations would support their actions against the school authorities. However, their reactions when she asked for their support were far from what she had expected. They never considered the school problem as a disability rights issue and even tried to dissuade the parents from taking action. Similarly to Dae-whan, her direct experience of the conservative operation of the disability organisation strongly motivated her to set up a new kind of group that could advocate the rights of disabled children and their families. At the time of the interview, she was leading a parents' self-help group and was working actively in the hope that it would be developed into a representative organisation of disabled families.

CONCLUSION

This chapter has explored various motivations and reasons that prompt parents to become involved in parents' group activities. Some of the parents joined groups to obtain the information necessary effectively to cope with their child's problems, and knowledge about where and how to secure better services and schooling. Others searched for trustworthy relationships in which their experiences of parenting could be shared and mutually supported. The desire to meet others who had undergone similar experiences was one of the most common factors that led parents to join a self-help group. For a number of parents, their engagement in group activities was strongly motivated by their personal experience of direct discrimination and an awareness of injustice in relation to their child's rights. Some of the parents actively interpreted their experience of disablement and firmly believed that the enhancement of the parents' collective power is necessary for changing disabling institutional practices and fostering their children's inclusion in mainstream social life.

Although there were variations in the timing and extent of becoming involved in a parents' group, the parents in this study came to see working together with other parents as a crucial part of their daily parenting activities. The next chapter will explore how the parents further develop their critical consciousness of disability problems and reconstruct their parenthood by working together in a parents' group.

CHAPTER EIGHT

WORKING TOGETHER:

THE DEVELOPMENT OF PARENTS' DISABILITY POLITICS

INTRODUCTION

In the previous chapter, I explored various motivations prompting parents to become engaged in self-help groups. I emphasised that their motivations were firmly grounded in their experiences of disablement, which ranged from unmet parenting needs, isolation and the deprivation of ordinary life chances to experiences of direct discrimination. It also argued that their involvement was a part of the process of seeking personal solutions to the problems they encountered, at the same time, empowering them to challenge the disabling social forces.

This chapter explores how parents develop their politics of disability by working together in self-help groups. It first examines how they develop their voices and empower each other, focusing particularly on their practices of sharing experiences. It then examines the ways in which parents develop their own community and the various kinds of group activities are performed. The third part of the chapter investigates how parents develop critical notions of disability and the kinds of counter values they create. In the last part, I explore the ways in which parents challenge and transform disabling practices through collective action.

SHARING EXPERIENCES .

In considering the development of politicisation and resistant consciousness, recent studies on social movements have noted the significance of 'safe or free space', in which members of socially oppressed groups can express their feelings about their suffering and exchange their life stories without worrying about others' negative responses (Gamsn 1996; Polletta 1999; Taylor 1996). Because disabled families in Korea suffer severe stigmatisation, parents find that the self-help groups, which they themselves create and control, constitute such a space. This section examines the ways in which the parents develop their understanding of suffering, construct their own voices in a collective way and forge empowering relationships, with a particular focus on their practices of sharing experiences in parents' groups.

Telling and listening to stories of suffering

For parents of disabled children, talking about their own experience of rearing such a child plays a vital role in helping them to reshape their identity in a positive way (Solomon et al. 2001). By sharing their experiences, parents come to understand that other people are experiencing a similar range of difficulties and problems. Finding common ground with other parents greatly helps them to recover from their previous experiences of loneliness, isolation and stigma (Huws et al. 2001; King et al. 2000). Furthermore, telling and listening to stories of suffering helps the parents to rethink their experienced reality in the wider social context and also develop a group consciousness (Rapp 2000). Thus, in many parents' self-help or advocacy groups in

Korea, telling their own stories of suffering is programmed as an important group activity. Those groups give the activity various titles. For example, it is called 'sharing our experiences' in the APCCP (Association of Parents of Children with Cerebral Palsy), 'revealing our problems' in the SAPHRDP (Seoul Association of Parents for the Human Rights of Disabled People) and 'talking together about our lives' in KPAMS (Koyang-city Parental Association for Mainstream Schooling). This activity is important because it greatly helps the parents to heal their damaged sense of self and move from internalised feelings of oppression to what has been called the 'free mind' (Hillyer 1993). Da-sol, one of the leading members of the KPAMS, described the process as follows:

We run a parents' camp programme. About fifteen parents participated last summer. Most of the parents were those whose children were enrolled in primary or middle school. There was a short programme entitled 'talking about our children's school life'. For many participants, it was the first time they had talked about it with lots of parents together...They opened their minds and told their stories about how they had been hurt by what the teachers had said and how the teachers and other children had treated their children...We scheduled it from 7 to 9 p.m. but it went on until midnight...Some parents cried while telling their painful stories...we consoled each other by saying 'You aren't the only one experiencing such things, it isn't your fault.'...It itself is a kind of process of healing our minds.
[Da-sol]

For parents, sharing their stories of suffering provides therapeutic benefits, and also a basis for a sense of empowerment. In telling their own stories and listening to those of others', parents come to acknowledge that their personal suffering is not merely idiosyncratic but forms a part of a larger group's experiences as a whole. This provides parents with not only a cushion against destructive emotions, such as desperation, isolation and depression, but also a social understanding of their

suffering. By confirming to each other that their problems are not caused by their personal limitations but by unjust social forces, the parents free themselves from feelings of oppression, such as self-victimisation and self-blame (Hillyer 1993).

Sharing stories of suffering is also an important process in which the parents can develop their own critique of the dominant interpretations of disability problems. Yun-seo, a leading member of the SAPHRDP, emphasises that this critical reappraisal of their problems is achieved by themselves rather than outsiders:

The programme called 'revealing our problems' in our group is fundamentally different from the educational programmes for parents provided by service institutions or professionals...I don't mean that they are totally wrong, but they talk only about what types of therapeutic programmes are necessary and focus on the success stories...For example, 'The mother is doing all these things to improve her child's condition. So the child can overcome its disability'...I think such programmes make parents feel that their challenges are more difficult...they strengthen feelings of guilt because many mothers are likely to think 'I can't do as much as those mothers' when hearing such stories...They don't discuss how much our families and our children are prevented from enjoying basic human lives. They don't talk about how to solve the problems...The programme in our group is different...we talk about how others make life difficult for us and for our children, and what would really make our life easier...we talk about how to change the system and how to change the law...I think it is a true education for parents.

[Yun-seo]

Her account clearly illustrates that professional-led educational programmes for families with a disabled child tend to be overwhelmed by rehabilitation discourse. It is apparent that professionals in such programmes define disability problems as the child's impairment and the parents' responsibility. It is also apparent that rehabilitation discourse is invested with a moral notion of what parents should do. Her story implies that it is often biased towards 'therapeutic parenthood'; that is, the

'good mother' is defined as unremittingly devoted to the improvement of her child's condition or to overcoming the child's tragedy (Gregory 1991). Yun-seo is certain that professional-led programmes do not reflect their lived reality of the mothers she knows and also reinforce their feelings of victimhood or guilt. As she emphasises, instead of being reliant upon the words imparted by others, the parents in the groups build their own definition of their suffering. By interpreting their problems and needs from their own perspective, they can cultivate alternative understandings of disability problems that run counter to purely therapeutic and individual solutions.

It is a widely held view that oppressed people can regain a sense of agency and begin to become personally and politically powerful when they find their voices, which are concerted in a collective way. As Hooks (1989) notes, finding a voice and developing new understandings of their reality from their own perspective constitute an act of resistance against the voice of authority. The activity of sharing stories of suffering in parents' groups can be understood as an important process through which parents free their 'silenced voices' and develop their own interpretations of the problems they suffer.

Supporting and empowering each other

In telling and listening to stories of child-rearing problems, the parents actively encourage and support each other. When others tell their stories, the parents try to share the tellers' feelings, emphasise their accounts of suffering, and counsel each other. Through words and expressions of feeling, they gain a sense of being loved, cared for, and valued. The blessed sense of acceptance and encouragement they

receive from other parents gives them the optimism and energy necessary to tackle other problems – whether these concern caring at home or dealing with service provision or institutional powers.

By forging such trusting and supportive relationships, parents give and receive a range of resources and help to deal with the problems they encounter. For example, the experiential knowledge and advice they receive from the other group members greatly help the parents to restore or enhance a sense of predictability and control. The parents also encourage each other to be braver in overcoming their difficulties and try to enhance each other's confidence and ability to stand firm against disabling forces. Such experiences have led many parents to regain a feeling of empowerment and become more active in claiming their voices. The parents in the study commonly said that they felt 'far more confident' when dealing with other people than they had before joining their group: they were more 'assertive', 'tougher' and 'strengthened.' For example, one father said:

After joining this group, I felt much stronger about the things I was fighting for...because I saw a number of other parents were fighting for the same thing.

[Jin-seok]

By sharing their experiences of parenting and hearing about the difficulties that the other parents have encountered, the parents come to expand their scope of concern and learn to understand other parents' suffering in a deeper way. Recognising that some other parents have lived a more painful life, the parents try to empathise with others' suffering; they also respect others' endurance of suffering and their struggle for a better life for their children. Through this mutual understanding and

acknowledgment, the parents are able to develop 'caring and nurturing relationships', which is endemic in their community building (Taylor 1996). Ji-min's narrative shows how parents understand other parents' lives and develop a stronger sense of belonging to a group:

In the past, I hadn't thought much about other parents and other children...I was only concerned about my child and myself. I thought, it would be impossible for me to care about others...I just thought that struggling with my child's problems was difficult enough for me...But after meeting many other parents in this group, I feel I've changed a lot...I'd like to think that I've matured a bit more...Some mothers have children who have a more severe impairment than my child. Some mothers have to rear two disabled children and have lived a harder life than mine, but their faces are much less troubled than mine. They have shown me great courage that I couldn't imagine before...I really respect those mothers...I sometimes thank God that I can be these mothers. Whenever I face a difficult situation, I try to remember them and their courage...Now I really feel all the mothers in the group are like my family and my sisters, not just parents.

[Ji-min]

During the interview, Ji-min stressed several times that working with other parents gave her the opportunity to cultivate new understandings of them. As she commented, since she had acknowledged that other parents were struggling to manage their lives without losing their confidence in a more difficult situation, she was encouraging herself to be braver in overcoming the difficulties she was facing. By gaining a deeper understanding of the lives of other parents and their children, she had also built a stronger feeling of intimacy and had come to see commitment to other parents as her new career.

Sharing their experiences can act as a catalyst for the parents' fostering of resistant consciousness and invoking their personal or group activism in their everyday lives (Rapp and Ginsburg 2001). Through formal and informal meetings,

and sometimes by forging virtual relationships, the parents were enthusiastically engaged in a discussion about their experience of childhood disability, the poor quality of education at school, the lack of work opportunities once their children were old enough or the deprivation of their children's ordinary life chances in the community. The more the parents talked, the more they became 'fired up' to tackle the issues, created a vision of a better situation and worked toward realising their vision (Dybwad 1990; Solomon et al. 2001). In order to facilitate this, many groups tried to disseminate to their members the stories of the parents' personal or collective struggles to change the disabling conditions. Dong-keon, a leader of the KAPDC (Kimhae-city Association of Parents of Disabled Children), underlined the significance of sharing stories of struggle in relation to the parents' empowerment:

Sharing information about services and knowledge about their child's impairment is important for parents...But it is also important for parents to share their experiences of fighting against schools, service provision institution, local government and whatever...When parents hear and witness the results that other parents had achieved, they can actively commit themselves to take action to change the environment that discriminates against their child...So we think the stories of struggle are important material and try to have parents hear the stories when we arrange group meetings...And try to have other parents hear the stories and get some inspiration from them...I think it's a good strategy for parents' groups to make their members become energetic advocates for their children.

[Dong-keon]

Dong-keon makes it clear that the most effective strategy for empowering parents is to help them to share a belief that the given situation can be changed and successfully reformed by the parents themselves. As his account implies, sharing their stories of struggle and triumph as well as suffering is crucial in facilitating the parents in the groups to approach disability problems from the social and political perspective and

also in fostering their resistant consciousness.

DEVELOPING A DISABLED FAMILY COMMUNITY AND CULTURE

By sharing their experiences, the parents come to acknowledge that they experience a similar range of problems, forge mutually supportive relationships and share a belief that they can use each other's strength and ability to solve their problems. This section examines the main features of their community building and which cultural values are developed in the process.

Embodying a collectivistic parenthood: from 'my child' to 'our children'

Because of the social dominance of the medical notions of disability, the parents are likely to perceive differences among disabled children (and their families by association) according to impairment-specific categories or the degree of impairment effect (Barnes et al., 1999). This conventional thinking can lead parents to hold the idea that their experiences cannot be shared by the parents of children with different impairments, and to internalise a 'hierarchy of impairment'. This can function as a barrier to developing their collective identity in constructive ways. Many of the parents in this study found that their continual working with parents in the groups provided new opportunities to free them from such conventional differentiation between disabled children (and their families). Min-joo described the change in her perceptions of children with different impairments from those of her son as follows:

I had thought the children like my son were living the most difficult life...to speak frankly, in the past...when I saw people with a physical impairment in wheelchairs on TV, I hadn't felt sympathetic toward them...I just thought 'Compared to my child's difficulty, your difficulty is nothing'... I just thought they were totally different from my child...but since I started to work together with other parents I've come to know many different difficulties of other types of disabled children; for example, the mobility problem...I'd never realised how serious the problem was...Even though I was the parent of a disabled child, it seemed that I'd built a wall against other disabled families.

[Min-joo]

Min-joo's son has intellectual and behavioural impairments. Before becoming involved in the group, Min-joo seemed to assume that her own experiences of rearing could not be shared with other parents, especially of children with physical impairments. However, by listening to the other parents' caring experiences, she came to acknowledge the different disadvantages that their children were experiencing and extend her concerns beyond her own child's impairment-specific problems.

Yun-ji, a leading member of the CAPDC (Changwon-city Association of Parents of Disabled Children), also commented on the importance of the mutual acknowledgement of difference in relation to the development of a shared sense of community:

Last year, one mother was going to send her son, who had an intellectual impairment to, the [special] school, but other mothers in the school objected to his admission...because the school's children all had a hearing impairment or physical impairment. The mothers thought the child would hamper their children's education...I felt so hurt when I heard the news...The parents' group is important because we can meet various parents with children with different disabilities...we learn from others we didn't know before about different children...The more parents meet and talk, the more they understand each other. Parents come to think 'Aha, they're same as us'...We always say in this group, 'If we don't understand each other,

how can we expect others [without a disabled child] to understand us? We don't have to be divided according to mainstream school or special school. Our children are the same in the sense that they don't receive a good education, and they are isolated from society regardless of the types of impairments'.

[Yun-ji]

As Yun-ji's comments imply, gaining a deeper understanding of difference among children is important in the development of community from at least three perspectives. Firstly, it greatly helps parents to diverge from the conventional differentiation of disabled children based on impairment-specific effects and this prompts them to extend their concerns beyond their own child's specific needs. Secondly, it enables them to consider other children's problems, which might not be directly related to their own child, as a part of the problems of their community. By reframing their unique experiences of rearing in more favourable collective and structural terms, the parents come to reinterpret their commonality making from the notions of social experiences of disablement. Thirdly, the parents share a belief that the good of other children can not be separated from the good of their own child, and embody a more generalised care ethic or an altruistic view of their own role.

The growth of mutual acknowledgement and a shared sense of community encourage the parents to redefine their parenthood in a collective sense. They no longer focus merely upon the welfare of their own child, and sometimes prioritise another's needs. Even though their own children may not receive benefit directly, the parents come to commit from the perspective of 'our children' and 'our family'. Jeong-eun's narrative shows how the parents reconstruct their parental responsibility in a new way through continually working with other parents:

The reason why I continue working in this group is not that my child benefits...I have to spend extra money, time and energy working here... in a sense, my child is disadvantaged...If I only thought about my child, I could bring him up well, even if the social situation didn't change...I'm Catholic and knew many people in care institutions run by the Catholic Church...My husband, the child's two siblings and I love him...We're confident we can give him a happy life...But it's not enough for me that only my child and family should live well. There are a number of children whose parents are ill and poor... there are so many children sent to institutions because their parents are poor or because they have no one to take care of them. I couldn't turn a blind eye to those children...Even though they aren't my blood, they are my children too.

[Jeong-eun]

Like Jeong-eun, many parents gradually reframed their parenthood in a collectivistic sense. In particular, as Jeong-eun's comments show, their sense of 'our children' went beyond the group members; they embraced, as a part of their own parenting, the duty to take care of those children who are more marginalised or excluded among disabled families. Nurturing care ethics and collectivistic parenthood constituted a most important (cultural) capital in their community development. It prompted many of the parents to commit themselves to group activities without respite after fulfilling their own needs, and it also enabled their groups to overcome some of the organisational constraints; for example, financial limitations, diverse members' needs, and the daily demands of care.

The generalised sense of care ethics and collectivistic parenthood were also actualised in some of the parents' activities. Many groups operated in accordance with similar normative principles in providing services for their members: for example, 'We always see everything from the perspective of children with severe impairments' (APCCP), and 'We give priority to the children who find it more difficult to participate in social activities' (SAPDC). Furthermore, despite the limited

resources, some groups tried to support more disadvantaged families in society. For instance, the KAPDC held the principle that at least ten percent of their total services should be offered free of charge to the children of single parents or of low socioeconomic status, even though those families were not members of their groups.

Cultivating a new identity

I mentioned above that the parents' groups act as a 'free space' in which the parents can express their true feelings of suffering and share their accounts of their experiences. In such a space, the parents can also develop new definitions of their identity and cultivate new values related to living with a disabled child.

In Korean society, the prevailing image of the parents of disabled children often includes notions of being victimised, powerless and incompetent. Thus, the parents in the groups actively challenge these negative images imposed upon them and, by placing great value on their personal strength and growth, try to help each other to build a new understanding of themselves as knowledgeable and resourceful individuals. Soo-heyon, a leading member of the KPAMS, explained how her group tried to enhance the participants' positive perceptions of and feelings about themselves:

This is a very supportive group...We renew our spirits together here...We support our strengths rather than our weaknesses. We never dwell on the negative but positively focus on improvement, you know, how to speak in support of our children...We try to make parents believe in themselves...We help each other to rediscover our strengths and abilities by discussing and exchanging experiences and ideas

[Soo-heyon]

In Korean society, in which the parents' social worth resides in their association with healthy, bodily perfect, competitive, intellectual children, the parent who rears a disabled child is described as less than a full parent. In addition, the prevalent cultural images of parents of disabled children define 'good parenthood' in apolitical, usually therapeutic terms, and focus on individual achievement: for example, devoted, self-sacrificing parents who make heroic efforts to overcome the child's tragedy are celebrated (DPF 2002). The parents in the groups actively challenged these externally defined, controlling images. The following two narratives excerpted from the newsletters of the parents' groups indicate how the parents in the groups reframe their identity and redefine the meaning of 'good parenthood':

I don't want to be 'the angel-like [self-sacrificing] mom' any more. I want to be 'the fighting cock-like [activist] mom'. I don't pray to go on living one more day after my child dies. I pray to be given the power to change this society into one where my child will live well even after I die.

[From a KPAMS newsletter]

We are perfect parents because we are rearing our children in this terrible society. We are strong and valuable parents because we are pioneers for making this society better.

[From an APCCP newsletter]

The image of 'the acting parent', a phrase used by one interviewee, was central in the reframing of their (collective) identity in a new way. As implied in the above narratives, the parents place a great value on acting on behalf of their children and on challenging the disabling authority and they praise each other's efforts to change the existing environment. In the group, the meaning of 'good parenthood' is actively reshaped in relation to the social reforms and in political terms.

As well as developing a new image of the self, the parents actively

reinterpret what it means to live with a disabled child. When they talk about their life stories about their experiences of rearing a disabled child, the parents do not focus merely on the difficulties and problems; they also actively share the rewards they have gained through their experiences. For example, the APCCP allots a special column, entitled 'Special Child and Special Gift', in its newsletter to the members to write about living with a disabled child. Jae-ok, who has been involved in publishing the newsletter, explained:

One of the themes which runs through the parents' stories of living with their disabled children is how much the parents learn from the children...in patience, in humility, in tolerance and compassion...so much understanding of weaker and vulnerable people...Many parents said that, 'If the child hadn't come to me, I wouldn't be concerned about other people who are suffering in this society. I might have remained a selfish person'...We learn the true values of life from our children.

[Jae-ok]

It was quite common for the parents to describe their child as a 'gift.' They stressed their children's precious contribution to their family life, and also showed a great awareness of their own transformation in telling their life stories. This particular collective expression of their journey in the groups offers a powerful challenge to the 'deficient' and 'tragic' image of their children. By transforming the child with an impairment from a perpetual receiver into a giver of special gifts and meanings, the parents portray their children's dependency as their unique opportunity to learn about unconditional love and gain a deeper understanding of social suffering. Rather than represent their disabled children simply as the givers of suffering, the parents reframe them as a 'lesson or enlightenment of a sort' (Landsman 1999).

In working with others, the parents actively challenged the deficient and

pathological images imposed upon both their child and themselves. In many ways, they tried to create alternative meanings in which their children's difference and their unique experiences could be revalued and praised. This cultural politics was a crucial part of the development of their community.

Developing collective care and advocacy

The parents' self-help groups are not generally substituted for the existing support or helping networks that the parents use (Pizzo 1983). However, when there is no available social service or the existing care systems do not meet their needs, the parents try to create an alternative space in which their children (and their other family members) can be properly cared for and supported (Dybwad 1990). The APCCP was one of the parents' groups creating an alternative care centre, named the 'Caring Together Home (CTH)', in order to support their community members. Ji-soo, who is currently head of the CTH, explained the need for such a place:

After I got became in this group, I met many mothers who were experiencing the same problems and needs...we needed to take a rest, at least one hour every day...our children needed to receive more attention, good therapy and care than anyone else but there was nowhere to send our children...Among those mothers, at that time, two were pregnant [with their second child]...So we thought, 'Let's help each other, share our caring'...We started it from one mother's apartment.

[Ji-soo]

Six mothers, including Ji-soo, played leading roles in initiating the CTH. They had children with multiple impairments or a severe impairment [diagnosed as cerebral palsy]. Understandably, the desire to solve their daily childcare problems was the main motivation for their collaboration in creating the place. At first, the CTH took

the form of rotating their caring work, and pooling their resources to pay together for regular visits by a number of therapists in order to provide high-quality therapeutic treatment for their children and reduce the need to travel every day to access services. However, once their efforts had become known through their newsletter, they received a great deal of support and respect from the group's members; for example, one older parent provided her house and worked as a voluntary carer for the children. Eighteen months later, with funds collected through donations from the members and private charity, the APCCP built a new building, which was installed with facilities designed to care for children with severe impairment. When I visited the CTH, it was caring for eleven children with severe and/or multiple impairments, providing a number of therapeutic services from two permanent therapists, and some children were receiving regular educational services from voluntary special education teachers. It was also employing five paid carers with the city council's financial support. Creating an alternative place for the families of children with a severe impairment is an important group advocacy activity because those families are likely to be particularly vulnerable and experience multiple disadvantages, such as the need for constant care, financial insecurity, and difficulty of access to care services. Ji-soo explained:

I think this place is unique in Korea...We don't exclude any child, however severe the impairment...Day-care centres for disabled children, not to mention nursery schools, still don't accept our children if they have a severe impairment or multiple impairments...I believe this place is very important for some families...for example, one mother using this centre had two children with cerebral palsy. They are brothers and the older one needs almost 24-hour care. Owing to her husband's illness, she had to make money and couldn't care for the children any more...before she came here, she had no option but to send the two children to an institution.

[Ji-soo]

Providing advocacy has been crucial in the development of the parents' groups. Much of the advocacy on behalf of others has been conducted by the members rather than by leading staff or the organisation. All of the advocates have been fuelled by their shared experiences of suffering and injustice. The linked issues of deprivation of the rights to education and discrimination in schools provide an example of parents' group advocacy. Tae-hee, one of the board members of APERDP (Association of Parents for the Educational Rights of Disabled People), described her group's activity as follows:

Because we always share the children's life in school, we know the environment of each school well...We record how much our children participate in the school activities in each school...If a school provides a good service programme for our children, we use it a kind of evidence to urge other schools to accept the programme...There are really a great many cases of discrimination against our children in school, such as the denial of admission, the teachers' maltreatment, sometimes physical abuse...When such things happen, we go to the school together, with veteran parents who have already fought on the issue...Alone, a mother may be afraid to fight and be tempted to give up.

[Tae-hee]

Group advocacy by parents on behalf of other children and their parents is the most helpful and powerful kind of advocacy because the advocates share the pain of exclusion and discrimination and understand the situation better than anyone else. As well as providing alternative resources and services, advocacy to secure their children's rights has been a crucial component of the groups' collective action to facilitate the empowerment of their community.

DEVELOPING DISABILITY CONSCIOUSNESS AND COUNTER VALUE DISCOURSES

By participating in various group activities, many of the parents of disabled children develop a social and political consciousness of disability. This consciousness does not arise simply from their involvement. Rather, they develop their consciousness through a series of collective reflections on their disability problems. As discussed in the previous sections, through sharing their experiences and creating new collective self-understandings of suffering, many parents come to define the disablement that their children and families experience as a social problem. They also reconstruct their parenthood in more political terms through their new experiences in the parents' groups, such as collective advocacy, challenging institutional power and direct political action. Through these activities, the parents develop critical notions of disability, raising resistant consciousness and challenging disabling forces. In exploring this development of the parents' political consciousness, this section focuses on the ways in which the parents interpret disability problems and examines the core counter values constituting their disability consciousness.

Disablement as social creation and social responsibility

It is important for the parents to acknowledge that the personal difficulties they encounter in parenting a disabled child stems not only from their child's impairment but also from disabling social system. By resituating their personal problems within a wider social context, the parents can liberate themselves from internalised oppression

and claim their rights as well as those of their children. Those who shift their understanding of suffering from the individual and family to the social context come to see clearly that the disablement that their children and their family face is created by the social environment. Dae-whan's narrative illustrates this perspective:

Within this hard situation, we really make efforts to rear our children well...The parents personally spend lots of money on educating our children so they'll be able to work...It's not for the sake of making money...To our way of thinking, we do it because our children are also members of this society and they have the right to enjoy their life with other people...But, as you know, there is little opportunity for disabled people to get a job...Because society doesn't give our children even a chance, the parents' efforts seem to be useless...A parent can and should help the child to develop his ability in a better way, but there are barriers that the parents cannot overcome.

[Dae-whan]

Dae-whan argues that, even though the parents try their best to prepare their child for inclusion in society, there are substantial barriers that they cannot overcome through their personal efforts. He also insists that disabled children's exclusion is a process of deprivation of equal opportunity to participate in ordinary social activities, and he clearly identifies the problem as the responsibility of society, which fails to take account of the needs of disabled children.

Yun-seo offers her definition of disability, underlining the able-bodied (or able-minded) focused social system, which creates the various forms of disablement encountered by families with a disabled child:

It's true that living with a [disabled] child is difficult...but it's just inconvenient...I mean, it's not such a tragic thing as others think...I think that the disability problem comes from the failure of the system...because everything in society is organised for only non-disabled people...for

example, when parents want to take leisure...if the social environment supported such a basic thing, the parents wouldn't think of our life as tragic...But, within the current social environment, rearing and living with a disabled child is too difficult...so the parents blame their own child sometimes and think that their lives are useless.

[Yun-seo]

Yun-seo rejects the conventional idea that the difficulties of parenting a disabled child come from the child's impairment *per se*. While the child's impairment demands that the parents conduct additional or special tasks, she stressed that the difficulties that the parents cannot cope with are mainly caused by the unsupportive social environment. She also insists that the psycho-emotional damage experienced through rearing a disabled child; for example, a negative perception of the self, and feeling that one's life has been frustrated, can be healed by changing the disabling social environment, rather than through individual coping. Yun-seo goes to say:

Disability isn't just a matter of the family...It can't be solved unless society changes...it needs a total effort: the public, government and society should work together to solve our children's disability problems...To achieve this, we must come together as parents, unifying our power and never stop insisting that our child's problem is a social issue. This is what we have to do now.

[Yun-seo]

The family has been regarded as the sole provider of disabled children's welfare in Korea. Public support for the parents of disabled children has seldom been treated as a social issue. By challenging this family-focused solution to disability problems, Yun-seo demands that society should be responsible for securing the rights of both disabled children and their parents. Thus, for her, the disability problem is no longer a personal or family problem; rather, it is a social and political issue. Like many

parents, she makes it clear that the enhancement of the parents' political power is a prerequisite to bringing about change.

Disability, human and civil rights

The notions of equality and justice are central to parents' development of the political consciousness of disability. Unsurprisingly, this awareness comes from their grounded experiences of injustice, the pain caused by discrimination, and the daily battles to protect their beloved children from the disabling society (Dybwad 1992; Murray and Penman 1996). Every day, in every part of Korean society, disabled children's basic human and civil rights continue to be contravened – unknowingly as well as deliberately. Disabled children have been deprived of the opportunity to receive the services deemed appropriate to their development and to conduct ordinary social activities because of the lack of social support or systematic social exclusion (KWSS 2002; S. Park 2001). In various respects, disabled children have been treated as less than human, resulting in segregation, discrimination and sometimes physical violence (RIDRIK 2001).

By defining their child's social exclusion as a process of the deprivation of his or her human and civil rights, the parents claim that it is society's responsibility to secure their children's right to life as the equals of non-disabled children. Eun-kyeong argues that the social recognition of the full humanity of disabled children is the precondition for securing their civil rights:

Our children have the right to receive the same respect as other people...Our children are different. But difference is just difference! This society isn't just

made up of normal, healthy people...All kinds of people are living here. Anyone can be born with an illness or become disabled. Everyone will get old someday...There have always been people needing others' care, and I think that the right to be well cared for is an important human right too.

[Eun-kyeong]

The notions of the diversity and vulnerability of human beings are central to Eun-kyeong's claim that disabled children should enjoy full human rights. She clearly argues that society needs to perceive disabled children as one of the diverse groups constituting society. She stresses that a disabled child's impairment is one of the characteristics constituting his or her humanity rather than a reason to treat him or her with less dignity. She further argues that the disabled child's need of others' care should not be interpreted as legitimising the denial of his/her citizenship rights.

In claiming their disabled children's human and civil rights, the parents not only focus on equal opportunities or treatment, but through their grounded experiences of disablement, they come to realise that equal access and participation cannot be secured solely by equal opportunity, and that, in order to secure their children's rights, they have to change the traditional perceptions of the 'special needs' of disabled children. Tae-hee commented that:

Shouldn't our children receive different treatment as a matter of course? Because our children are different and have unequal ability, they deserve to be treated differently. Our children have to be given more attention and help if they're going to do as much as normal children...But people think we're demanding special favours...We shouldn't think of it as charity...It's about our children's basic rights...and providing necessary aid to our children is society's responsibility...We have to keep struggling with the distorted understanding of our children's needs.

[Tae-hee]

The notion of the different needs arising from a child's impairments is central to Tae-hee's argument in favour of disabled children's civil rights. She strongly challenges the beneficiary notions of the disabled child's different needs, which are deeply embedded in Korean society and welfare regimes. Instead, she claims societal recognition of the disabled child's different needs as public goods, arguing that meeting those needs is society's responsibility, and clearly identifies fulfilling the child's different needs as the precondition to securing disabled children's equal rights. She stresses that changing old-fashioned ideas about the 'special needs' of disabled children is one of the crucial projects of parents' activism.

Disabling values and enabling values

In developing their social and political consciousness of disability problems, the parents also create their own counter-value discourse against the dominant disabling values surrounding their children. To borrow Fraser and Gordon's (1997) words, to 'rehabilitate dependency as a normal, even valuable human quality' was crucial to their counter value discourse. For example, Dong-min emphasised that disabled children's dependency should not be identified as a mark of being 'abnormal':

Because our children have disabilities, they need other people's help...But receiving help from others is nothing to be ashamed of...It's fair that people with more ability should help others with less ability and that healthy people should care for sick people. When an old person can't carry a heavy package, it's a natural obligation for a healthy young man to help them because he has more ability. I think it's just the way people live together in society...But people only think of our children as a social burden.

[Dong-min]

The notion of interdependent relationships is central to Dong-min's understanding of disability. He insists that being dependent upon or receiving help from others should not be identified as a mark of inferiority. By acknowledging that dependence is a natural part of human relationships, he insists that disabled people's dependency upon others should not be considered as different in kind from other relationships in which help is given and received. He further argues that the caring work and relationship that disabled children engender should not be understood only as a burden. He goes on to say:

My child gets a lot of help from his [non-disabled] friends...But I don't think of him as only a receiver of help...In certain ways, I believe, my son also contributes. They might learn something from him that will enhance their personality and morality...I think, because they're growing up with my son, they'll just think it's natural to care about someone who needs help or is weak...That's why we encourage parents to send their [disabled] child to mainstream school...Because our generation grew up without seeing disabled people, people think disabled people are just a burden.

[Dong-min]

Tronto (1993), in her exploration of the political concept of care, emphasises that the human qualities emerging through a caring relationship do much to inform the practices of democratic citizenship. Similarly, Dong-min points out that the caring work and relationships that disabled children engender do much to teach others about the ways of 'being together'. He further argues that they contribute to the development of mature civic virtue (for example, the tolerance of difference) and inform the practices of responsible citizenship.

Like Dong-min, many parents identified the presence of disabled children as a kind of valuable challenger that serves to enhance social organisation and

relationships, rather than being a social burden that should be eradicated as far as possible. Woo-seok commented:

As you know, disabled people's long fight for the right to mobility established the regulation to install facilities in tube stations...Now there is an elevator for disabled people in many tube stations. But they aren't only for disabled people. The elderly, pregnant women and parents carrying babies all benefit from them...In the same way, if the social environment is changed to one where disabled people are respected and live well, I think society will be much more convenient for everyone...Everyone will be treated more equally than they are now.

[Woo-seok]

In claiming public recognition of their child's needs and rights, parents do not simply approach these issues from the perspective of self-interest; they also approach disability problems with a vision of the enhancement of the welfare of the wider community and of the well-being of society. Such value discourses (for example, the re-evaluation of care) tend not to give rise to direct political confrontation with disabling practices, such as the denial of the right to equal education. However, those value discourses that the parents have created, disseminated and shared within the groups reinforce the legitimacy of their claims and their moral authority, which allows their resistance to be developed further.

CHALLENGING THE DISABLING SOCIETY

In the previous sections, I have explored how parents challenge and re-interpret the dominant perceptions of disability. I also discussed the ways in which the parents

reconstruct their parenthood in social and political terms. This section explores how their developed consciousness of disability and politicised parenthood come to be actualised as a form of collective activism.

Enhancing public awareness

Uri-ai-dereonaegi [making our children visible] has been the shared rhetoric framing the parents' group activities designed to change the social attitudes towards disabled children. For instance, at the parents' meeting in which I participated, one older parent said:

Rather than waiting for people to change their attitudes, we have to get them to acknowledge our children...*We have the responsibility to make our children visible...* Don't just stay in your home. Don't be afraid of going to public places. Show people that our children exist. Let other people see, talk to, and get to know our children...We have to tell them...*'We aren't ashamed of our children, we love our children, we're as proud of our children as you are'*.

[From field note 14-04-2004]

The parents in the groups generally perceived that the social invisibility of disabled children had contributed to the perpetuation of distorted and prejudicial attitudes towards the children. Thus, letting their children be seen in public, everyday settings – 'collective coming out' as one group termed – was regarded as the first step in the promotion of other people's understanding of disabled children. On a broader front, the parents groups' 'collective coming out' aimed at overcoming the strong stigma and fear attached to the children's impairment and enhance the social recognition of the children's full humanness. Seo-hee explained why, in its early years, her group

needed to take the children for walks in the street:

It [walking in the street] was, in itself, very important to make people acknowledge there are quite a number of children with Down's syndrome. Now people's perception of our children is much better than before, but, at that time, people didn't know children like ours existed...And, even if they did know, they thought such children were from defective families...It was necessary to get people to think of our children as just children, and of us as ordinary, normal families.

[Seo-hee]

In the early stage of parents' groups, most group activities were usually focused on giving their children the opportunity to participate in ordinary social activities such as leisure activities. When they conducted these events, many groups saw them as an opportunity to enhance other people's understanding of their children. Ji-min described how her group tried to create a public awareness of their children:

I feel that people's perceptions of disabled children have changed a lot since we started to do programmes, such as 'going to the library together', 'swimming school' and 'weekend travelling'...At least three years ago...even the city council had no idea how many disabled children were living in this city. So, when our group first came together...We borrowed the city council's assembly hall whenever we offered programmes to our children...you know, over one hundred disabled children came to see the movie that day...People saw all kinds of children with different disabilities...When they saw them, people were surprised, and said 'We didn't know there were so many disabled children in this region'.

[Ji-min]

Dong-keon also emphasised that his group's events had been carefully planned to help other people to acknowledge their children as ordinary members of the community:

Our group activities are not merely for us. We always emphasise that ‘the local community should go forward together with us. We’re members of the local community too, so the community should change its perceptions and images of disability’...This motto best represents our viewpoint when we are planning events for our members.

[Dong-keon]

When I interviewed him at the group’s office, Dong-keon showed me several photos of events that his group had organised. ‘The Festival for Disabled Children’s Rights’ was one of the biggest. Since 2000, the group had held the festival annually for three days in May and it had come to be known as one of the most important local community festivals. As well as non-disabled people’s cultural performances, the festival included performances by disabled children and various events designed to raise public awareness of disability problems; for example, showing a documentary film about disabled people’s fight for mobility rights. Dong-keon described its results very positively:

During this festival, almost all of the families in our organisation come and enjoy it with other people. So we don’t really have to make any effort to encourage people to understand our children better. You know, just by seeing our children and enjoying being with them, people come to know our children naturally and change their perceptions of disability...We feel other people’s attitudes have changed a lot...Many parents say they don’t have to put up with disapproving stares any more when they go to public places... And now many people and organisations give great support when we need help...I think it’s a big change from what we experienced in the past.

[Dong-keon]

The disabling images and stereotypical, distorted representations of disabled people in the media have been widely noted as one of the mechanisms reproducing the oppression of disabled people: disabled people are portrayed as ‘abnormal’, and the

disability problem is individualised (Morris and Finkelstein 1993; Shakespeare 1994). To change the prevailing negative cultural images of their family life, and also to expose the discrimination and prejudice that their children face, some of the groups in this study actively sought alternative ways of representing their experiences and disability problems. Among others, the activity of a group of mothers in the TAPDC who are known as 'the mothers who are breaking down barriers' provides a good example of the parents' cultural politics of disability. Mi-jeong explained her motivation for becoming involved in the group's activity by referring to the problematic representation of families with disabled children:

I think there are only two versions [of representing families of disabled children in the media]...The family with a disabled child is so pitiful and miserable; otherwise, we hear only stories of overcoming disability or some very great mother's story...for example, the mother who made her son a swimmer good enough to win a silver medal in the Asian Games...It doesn't help us or help people understand our children correctly...We have to let people hear real stories about our lives... How we love our children, how hard it is bring them up, the lack of services, and our children's problems in school...That's why we're planning to make the [radio] programme ourselves.

[Mi-jeong]

When I interviewed her, Mi-jeong and two mothers were taking a media production course, which was provided by a civil rights organisation. During the period of field research, she was unable to contact me about their progress. However, when I contacted her again via e-mail eight months later, she told me that an independent radio station had started to broadcast the programme they had made. According to her, the programme was being broadcast for an hour monthly and contained three main parts: the parents' stories about rearing a child; stories of discrimination; and a

lecture on disability issues, such as inclusive education. Eleven mothers are currently (as of August 2007) involved in this group activity and they make the programme themselves, from planning to the final stage of broadcasting. I was surprised that they were all mothers of children with severe impairments, playing a first carer role in their daily lives, and continued the activity even without others' support. They assigned different roles among themselves and helped each other: some mothers took on the task of interviewing parents; others wrote a script; and others took care of the children or helped with the domestic chores when the other mothers were working. In spite of their daily constraints, the reason for their commitment to cultural action is clear: to enhance the social recognition of their children's rights and to present their own stories, thus rectifying the distorted images of their children and their families. The introductory page of the book they recently published - which is filled with the parents' broadcast stories and pictures of their children - begins:

In this book you will find the real stories of our lives and pictures of our lovely children. Here are our stories of happiness, pain, sorrow and hope. Here are stories of the discrimination our children and our families have to suffer. Here are our stories of triumph, and stories of brave mothers and fathers who have been fighting for our children's rights...

[The mothers who are breaking down barriers, 2007]

The parents in the groups, whether individually or collectively, had actively sought to change the prevailing negative perceptions and images of disabled children. They had also, in many ways, sought to enhance public recognition of their children's rights and address disability problems. Such activities were a crucial part of these parents' cultural politics aiming at transforming the disabling society.

Intervening in institutional practices

By working together, the parents in the groups came to learn that their group's advocating roles could not be fully achieved without their continual efforts to intervene in institutional practices and transform them in accordance with their desires. Despite the variety of issues that the groups were addressing, their activities were grounded in the need to improve the day-to-day experience of their children and themselves as they come into contact with care, educational, or welfare systems. The parents' collective interventions in institutional practices were driven by their scepticism about the good will of the public agencies. They were not confident that professionals or the bureaucracy could be trusted to improve the welfare of their children. As one mother put it, 'If we don't keep on demanding that our children's needs are met, if we don't apply some pressure [on the service providers or government], the services for our children won't be improved'.

From an early stage, most groups had actively sought the improvement of public social services for their children, usually at the grassroots level. However, they were not solely concerned about the expansion of service provision; they also sought to assert the authority of their voices, and so change the balance of power within the existing services, education system or welfare regimes. Min-woo explained:

When we talk about service provision for our children with the city council, we always tell them 'Don't leave us out of the picture'. When we demand improvements of the service provision for our children, they excuse the shortage of services saying the problem is the limited local government budget...But what we're always pointing out is that, even within the limited budget, if the consumer and provider meet, talk and plan together, we can

achieve more effective results.

[Min-woo]

Like other user-led or self-help movements, such parents' groups challenge the power of professionals or the public authorities to define the nature of their problems and to determine the appropriate response to them (M. Barnes 1997, 1999). Parents demand recognition of their experiential knowledge, from which the service planners and providers can learn valuable lessons. In addition to the need to make their voices heard, active intervention in social service planning and decision-making is also necessary to change the traditional perceptions regarding the welfare of disabled people. Many of the groups pointed out that service provision for disabled children was still conducted on the principle of segregation. Jeong-hee, a leading member of the SAPHRDP, commented that:

Last year, the city council planned to build a swimming pool for disabled people...We welcome the council's decision to a budget for our children... but we rejected the plan because we thought it wasn't a good idea to make a special place that only catered for disabled people...We argued that it would be better to establish many new programmes in places that already exist...What we really want is for our children to use the same facilities and mix with other people; that way they'll be recognised as just ordinary members of the community.

[Jeong-hee]

One powerful way of challenging the existing institutional practices is to evaluate systematically an institution's performance and publicly distribute the results (Pizzo 1983). This tactic was used very effectively by some groups who were focusing on the improvement of social service provision. Dong-keon, a leader of the KAPDC, described the process and the group's activities in detail:

From the start, we were determined to play a leading role in changing the attitudes of [local] government staff and establishing good policies for our children...When we set up our organisation, the government had no welfare plan for our children. There were no specialist policies for families with disabled children in the local government...So we thought we needed to make a kind of blueprint about welfare policy regarding disabled children and their families...We hired six staff and obtained the assistance of some professionals...We gathered all the information about service programmes conducted in other regions, and about other local governments' budgets for the welfare of disabled people. We researched some of the policies and programmes developed in other countries...we also surveyed what kinds of services were available in this city, how much money the parents were spending to obtain services and what kinds of services they felt were necessary...We collected all his information. We used it as evidence to get the local government to draw up a long-term plan for the welfare of disabled people...We published a report on our research results and distributed it to many social organisations...and we utilised our members working for newspapers and broadcasting stations in order to make other people acknowledge our problems...I think that, because of our efforts, our parents' group came to be recognised as an important civil organisation in this city and the [local] government could not ignore our demands.

[Dong-keon]

Compared to the other groups in this study, the KAPDC had substantial organisational resources. For example, in addition to strong leadership, the KAPDC had developed effective networks with supportive professionals and other civil organisations (for example, the teachers' union), as well as among the parents themselves. Unusually, the fathers actively participated in group activities from the beginning – especially those who had previous experience of the civil rights movement or had professional jobs. The KAPDC also achieved financial stability by devising various fund-raising strategies. Drawing upon these organisational resources, the KAPDC conducted systematic research on the needs of families with disabled children. Through various group activities, including sit-in-demonstrations, they made the public aware of their children's problems and pressured the local

government to increase the budget for disabled families' welfare. As well as achieving the improvement in the existing social service provision, it piloted new social service programmes and formulated new policies regarding welfare services for families with disabled children. When I visited it, the KAPDC had built a referral system, which they called the 'one-stop service', and was running a number of service programmes with local government funding, such as 'respite care', 'one-day helper' and 'summer school'. The group had also made the local government set up welfare benefits for families with disabled children, such as 'care allowance' and 'educational allowance for disabled children', which were not offered by a national welfare scheme.

The parents' group seeks to expand their children's opportunities to receive better social services, and to create a social environment in which their children can participate in mainstream activities. In order to achieve these aims, groups actively intervene in disabling institutional practices in many ways. They also work to make society recognise that the parents themselves are instrumental in solving certain problems and also in initiating changes in wider service and welfare systems.

Building the parents' disability movement: embracing direct political action

In recent years, a growing number of parents' groups in Korea have begun to identify their group activities in relation to the development of the *Jangae-Boomo-undong* [parents' disability movement]. These groups – in particular, those that, like the groups in this study, are controlled by the young generation of parents – began to realise that their activities should not focus merely on service provisions intended to

meet therapeutic, health or care needs. While there are substantial variations among the parents' groups in terms of their involvement in political action, many groups have begun to include direct political action, such as sit-in demonstrations as a crucial part of their activities.

The emergence of political campaigning by parents was significant in various ways in relation to the development of the parents' disability movement in Korea. Firstly, and above all, direct political action was, in itself, a process through which the parents were inspired to join together, experiencing feelings of empowerment and witnessing their collective power. For instance, as many of the parents testified, on seeing one mother shave her head during the demonstration, the parents were shocked, inspired, felt a strong emotional bonding, and transformed their frustration into more energetic emotions, such as anger. Mi-jeong described her feelings of power and self-emancipation gained through participating in direct action:

Sometimes other mothers ask me why I'm going on this kind of demonstration. I always say... 'I'm going there to free myself'... When I'm with other parents there, I feel they are real comrades, not just parents... And by acting together, I feel I'm doing something valuable; I mean, I'm really doing my best for my child... It's real freedom and overcoming disability.

[Mi-jeong]

Mi-jeong's story implies that direct political action was a site in which the parents cultivated a 'culture of resistance', and which prompted them to embrace activism as one aspect of their parenting. Understandably, this experience has generated a growing number of activist parents, even though they want to be called parents rather than activists. It has also impacted upon many parents' groups, leading them to redefine their group identity against both conservative parents' groups and traditional

organisations that have been controlled by professionals.

Because disability problems are conceived as individual problems in Korea, it has been taken for granted that solving them is a family responsibility. The parents' groups in this study were convinced that direct political action would be a most effective and powerful way to relocate disability problems from the family context to the public domain. Moo-seong commented that:

I think that parents' demonstrations, whether they address educational issues or welfare services, are a most direct and efficient way of changing society's perception of the disability problem... Like other social movements, through demonstrations, we can make society recognise that the problems of children and families are social problems, not just family problems...

[Moo-seong]

Moo-seong confirms that direct political action is a powerful way to focus the general public's attention on disabling institutions and barriers, and show that the suffering of disabled children and their families are a matter of social relations, and not simply the result of the children's impairment.

However, direct political action is not just a means of raising public awareness of disability problems and achieving specific goals; it is also a process of collective identity formation (Oliver and Barnes 1998; Scotch 1988; Shakespeare 1993). The parents' direct political action in recent years has been crucial in developing their collective identity, which radically changed their understanding of their community and enabled the further development of the parents' disability movement. The parents' political campaign for disabled children's educational rights, led by the ADPER (Alliance for Disabled People's Educational Rights), is a good example of this process. It was conducted in the Korean capital, Seoul, in July 2004

and continued for 17 days. It aimed to reform the SEPA (Special Education Promotion Act) so that it would meet disabled children's educational needs and secure their rights in school; it also aimed to persuade the Ministry of Education to increase its budgetary allocations for disabled children's educational services (e.g., helper). The campaign involved the occupation of the building of the Committee for Human Rights building, and during the occupation, parents conducted various forms of demonstration, such as a sit-ins, hunger strikes, and *sambo-hangjin* [marching in the street with the sequence 'take three steps, kneel, bow']. The campaign caught the attention of the general public, received support from many social movement organisations, and came to the notice of several assemblymen. Because of the publicity, a number of parents' groups in the local regions joined the campaign. Every night, while the campaign lasted, the occupied building was the classroom in which the parents learnt about other groups' experiences, shared their tactics, and recognised the importance of coalition in order to overcome the obstacle of regionally separated struggles. At that time, the government did not respond to the campaign. However, based on the networking done during the campaign, the ADPER set up branches in many provinces and continually supported regional political campaigning for educational rights. Because I had to leave the research field (in August 2004), I could not observe the process. However, some of the parents in this study who were involved in the campaigning, such as Dong-keon and Tae-hee, later informed me that about its results. Tae-hee evaluated the achievement of the political campaigning in relation to the growth of solidarity and collective identity formation among parents' groups:

Through our campaigning we show our power as parents. That, in itself, is important, I believe, because many parents' groups are changing, becoming more active... The most important benefit we achieved is that more and more parents are thinking 'We have to act together. We don't have to be divided according to the type of impairment'... And more and more parents think that their children's educational problems are the same problem, whether their children are enrolled in special school or general school...

[Tae-hee]

In Korea today, the parents of disabled children are emerging as ardent political actors. They strongly reject the old image of them as powerless and are moving towards the further development of the parents' disability movement. Currently, fighting for disabled children's educational rights is a symbolic code in leading the parents' disability movement.

CONCLUSION

This chapter has explored how parents are developing their politics of disability through group activities in self-help groups. The parents' groups act as an 'alternative space' in which parents can create new, collective self-understandings of suffering and self-definitions of disability problems (Fraser 1997). By freeing their silenced voices and sharing their stories of suffering, and through collective reflection on their problems, the parents come to reframe their individual biographies in more favourable collective and structural terms (Taylor 1996). By connecting their personal experiences and everyday lives to social disabling forces and relations, the parents are developing their political consciousness of disability problems. In developing their community, the parents are also actively cultivating counter-

meanings, values and discourse against the dominant cultural codes of the disabled family and disabling values. This is also a process in which the parents reframe their parenthood in a collectivistic sense and in political terms. Embracing activism as an important part of their parenting, the parents engage in both personalised resistance and collective actions in order to break the institutional barriers to their children's rights. The parents' grassroots activism and their 'small democracy', which have been practised through self-help groups, are contributing to the emergence of the parents' disability movement in Korea.

CHAPTER NINE

CONCLUSION

INTRODUCTION

In this chapter, I return to the original aims of the study. The first part readdresses the fundamental perspectives applied to the research on the experiences of families with disabled children, and then revisits the research process reflexively. The second part focuses on the research findings and key themes in terms of the main research questions. The final part identifies and draws out the policy and practical implications in the Korean context and addresses desirable future research directions.

THE SOCIAL MODEL OF DISABILITY AND ITS IMPLICATIONS

This study is, first and foremost, about disablement as experienced by families with disabled children in South Korea, and aims to expose the inequality, disadvantages and exclusion that this group faces in their day-to-day lives. In exploring their experiences of disablement, this research adopted critical perspectives underpinned by the social model of disability. The social model of disability is a western concept,

especially manifested through disabled people's political movement in the U.K. It might be difficult to apply certain debates based upon the social model of disability directly to a society with a different history and culture. However, it is important to acknowledge that the social model of disability is neither a theory nor an ideology; it is an analytical tool or a way of thinking about disability problems:

It is important to remember here what the social model actually is. It is a model, which is what social scientists call a 'heuristic device' or an aid to understanding [...] In short, the social model of disability is a tool with which to gain an insight into the disabling tendencies of modern society
(Barnes 2007: 17)

To reiterate, the social model of disability rejects the conventional assumption that there is an 'inevitable' causality between having an impairment and being disabled. In this model, disability is redefined as the product of social forces and relations. Thus, it suggests that, in order to understand the restriction on their activities and the disablement that people with impairments experience, we must transfer our analytical focus from the individual bodily limitation to the disabling social environments. This fundamental view is used as a backdrop to study the experiences of families with disabled children: that is, on the assumption that 'there is no inevitable causality between having a disabled child and the disablement of the family'.

The research findings also suggest that the social model approaches are more relevant for understanding the parents' experiences and accounts from their own perspectives. Although Korean parents of children with an impairment are unaware of the critique of the social model approach, very many parents expressed a belief

that the real disablement that their child faces is not his/her physiological impairment but others' discriminative attitudes, the inaccessible environment and the deprivation of equal opportunities to participate in mainstream social activities. That is, the parents make a distinction between the impairment and the disablement process.

SOME REFLEXIVE COMMENTS ON THE RESEARCH

It is clear that this research was substantially shaped by my own personal experience, intentions and values. In particular, my experience of living with a disabled brother and my experiences of disablement greatly impacted upon the research process. Rather than seeing it as 'biased' or something to be suppressed, I considered my personal awareness as a vantage point from which to obtain the insider viewpoints of the parents and on which to build friendships with the researched. However, the research process revealed some sensitive and ethical issues that I had to solve.

The development of reciprocity was one of the most significant factors that facilitated the parents' active participation in the knowledge production as well as in creating a rapport with them. To give the parents transparent information about my personal information, motivation, and a purpose of the research was an important task because, as I acknowledged, many parents had experience of being treated as just an object of curiosity. To get the parents to appreciate the researcher's sincerity and thus come to regard me as a kind of companion was very important in conducting the interviews.

Another important issue I should acknowledge was the cultural pressure

regarding 'good parenthood' which might make the parents reluctant to make negative comments about their family experiences because these may be interpreted as revealing a lack of 'parental competence' or 'parental love' by outsiders. Again, the development of a deep sense of trust was a prerequisite for them to tell their stories without worrying about eliciting negative reactions from the interviewer. This often required me to spend lots of time forming trusting relationships prior to conducting the formal interviews.

Another important ethical issue that I had to solve regarded the handling of sensitive and emotional problems, since, in many aspects, asking about stories of disablement is likely to create pressure through recalling the respondents' painful memories and causing unintended emotional damage. From my experience of the interviews, I learnt that the interview itself should be transformed into an empowering experience. In my case, sharing emotions, validating concerns and encouraging comments were an essential part of the interview process. For example, 'We should not give up. Our child's future will be better than now' were sentiments often expressed during the interviews. Indeed, much of the interviews were converted into conversations rather than adhering to a question-answer format.

EXPERIENCING DISABLEMENT

The research aimed to explore the parents' experience of disablement in rearing their child with an impairment. Families with disabled children in South Korea experience numerous interlocking facets of disadvantages and inequalities that other families

with non-disabled children would not encounter. The parents and siblings, like the disabled children, are also subject to stigma, exclusion and discrimination. Within this experience, three key dimensions were central.

Material, financial and practical problems

The families, in general, face greater chances of (long-term) material deprivation than families without a disabled child. Overall, the findings are reflective of the previous research on families with disabled children (e.g. Baldwin 1985; Baldwin and Carlisle 1994). Given the social circumstances in which caring for a disabled child is unshared, the presence of a disabled child greatly curtails the opportunities of the parent, especially the mother, to participate fully in the labour market. A substantial number of parents reported that, at a time when additional resources were required to meet their disabled child's additional needs, the loss of earnings had a decisive impact upon their families and increased the likelihood of them falling into poverty. The most common, consistent theme arising from the parents was the financial hardship that they experienced in meeting their child's special needs or services, which were regarded as essential for their child's development or well-being.

Disabling services and professionals

Despite the diversity of their individual/family background, the parents commonly encountered substantial barriers to accessing the range of information and services that would have a positive impact on their lives as well as their disabled children's welfare. Nearly all the parents reported that they had to devote an enormous amount

of energy and time to obtaining crucial information. In particular, at critical transitional periods (for instance, on discovering their child's impairment or when the child entered the educational system), a great deal of knowledge and information had to be sought out by themselves, causing great stress.

The lack of service provision for disabled children and their families was consistently identified across different groups as the barrier to fulfilling their sense of good parenting. Very many parents reported that they had suffered difficulties in receiving timely, appropriate services. They felt substantial levels of dissatisfaction with the available services, in terms of both their quantity and quality. Indeed, for many parents, coordinating the scattered services and seeking for better ones was the most stressful aspect of bring up their disabled children. In addition to the problems of their unmet needs for services, many of the parents experienced significant difficulties in building partnerships with, and in receiving collaborative support from, the medical, educational or other service providers.

Discrimination and exclusion

The parents' accounts reveal that there is considerable common ground between the Korean parents' accounts and those found in the broader literature on disability and oppression (e.g. Dowling and Dolan 2001; Read 2000; Read and Clement 2001). The findings show that there is clear evidence that disabled children face a variety of forms of discrimination and segregation, ranging from hostile attitudes, the denial of admission to mainstream facilities and the deprivation of their right to education. As well as disabled children, others in their families experienced unequal opportunities to participate in mainstream social activities, and were frequently shunned by their

peers and the wider community.

TRANSFORMATIVE EXPERIENCES: REWRITING DISABILITY

Another line of research questioning was how the parents transform their perceptions of disability (and their reactions towards their disabled child by association) through their on-going experiences of parenting. Whilst the parents in the research did not speak about them categorically, their accounts revealed that they made implicit references to three critical transformative experiences. To highlight the salient features of the parents' transformative experiences, I discuss them using the following typology.

Table 4 Typology of parental transformation

	Disembodied acceptance	Embodied acceptance	Emancipatory acceptance
The perception of the child's impairment	Bodily component (things to be cured)	Personhood component (Characteristics)	Variation of social groups
Core cognitive mechanism	Decoupling impairment from the child	Reflexivity Inter-subjectivity Thinking from the child's position	Social consciousness of disability problems
Orientation	Improvement (Rehabilitation)	Quality of the child's life	Changing Society

Prior to the birth of their disabled child, the majority of the parents in the

research had shared negative, stereotypical perceptions about disability and being the parent of a child with an impairment. The parents reported that, sooner or later, they found themselves involved in loving, care-giving relationships with their disabled children and abandoned some aspects of disabling values that they had been socialised. However, in their early period, a parent is likely to stand at the centre of a great paradox, saying that, as Landsman (2003: 1949) succinctly observed, 'I love you as you are, [but] I would do anything change you'. As she underpinned, such reactions towards their children cannot be explained by the conventional notions of 'acceptance/denial' which have been proliferated in the professional literature. In order to understand fully such a parent's paradoxical acceptance of a disabled child in that stage, we need to take into account the cultural and social forces. Under the cultural pressure for 'normality' and the dominant medicalised notions of disability, it is understandable for the parents to perceive their child's impairment as something to be fixed or modified in some way. Whilst the parents accept their disabled child (in spite of his/her difference), the child's impairment is likely to overshadow other issues. At the same time, the parents are inclined to perceive their parental roles and responsibility in therapeutic or rehabilitational terms. Such parents' paradoxical reactions towards their disabled children (usually in their early years) can be called a 'disembodied acceptance', in the sense that the child's impairment is decoupled from his/her personhood.

Through their continual caring practices, parents learn to see their child's difference in a new way. Through getting to know their child's unique tempo and characteristics, the parents come to perceive the child's impairment as a crucial component that cannot be separated from his/her whole personhood. As Hillyer

(1993: 120) notes, parents see their disabled child as a 'total integrated personality to an extent that makes it impossible to imagine the person without the disability, but that also incorporate the disability as just one part of the whole person'. As shown in Chapter 5, this transformative experience involves a development of intersubjectivity, which enables the parents to learn to think from their child's position. During this stage, the parents develop reflexive thought about their previous ideas of 'normality' and gradually move their primary orientation from rehabilitation to a broader sense of their child's quality of life. One mother in the research described this moment as the 'true acceptance' of her disabled child. I term such transformative experiences 'embodied acceptance'.

On the basis of the embodied notions of their disabled children, the parents developed further a moral-political judgement about their child's status quo and a critical interpretation of any disability problems. Whilst the parents' embodied acceptance is a crucial stage in changing their previous perception of disability and parental responsibility towards their disabled children (especially the divergence from orientation to rehabilitation), they were unlikely to overturn completely the view that the problems associated with their disabled children are basically individual/family issues. For nearly all of the parents in the study, shifting the roots of disablement from the child's limitations to society was a significant cognitive praxis. This involves a process of development of a social consciousness of disability problems, which are facilitated through the parents' personal and/or collective resistant activities on behalf of their child's rights. This transformative experience also entailed a process of reconstructing their parenthood in more social and political terms. In this stage, their notions of parental roles and responsibility are no longer

limited within the disabled child and their families. They gradually embrace more public and political 'disability work' in order to change the disabling social circumstances and perceive it as one part of daily parenting. I named this parents' transformative experience 'emancipatory acceptance'.

DISABILITY-PARENTHOOD: CONDUCTING INTENSIVE AND EXTENSIVE PARENTAL ROLES

Another line of inquiry was to examine how the parents of disabled children develop their notions of parenthood, and explore which parental roles they undertake in the process of the interplay between their children and the (disabling) social circumstances.

Traditionally, the parents of disabled children have been viewed as being the 'passive recipients' both of the stresses impinging on their lives and of the support services (Titterton 1992). A growing number of researches has challenged this view and has recast the parents as actively managing their situation (see, for example, Beresford 1994; Dobson et al. 2001; Sloper and Turner 1993). This research also supports this line of approach. There is strong evidence that the parents are action-oriented and have developed their own resilience in overcoming the problems and difficulties they encounter. The findings also show that the parents are creative in creating favourable environments for their disabled children.

Inequalities based upon disability are likely to demand that the parents perform multiple and extensive roles that other parents without a disabled child

might not undertake. Given that they live in a society where the disabled child is devalued, many parents felt that they needed to adopt additional roles in order to augment their resources and facilitate their children's acceptance. The findings show that many of the parents actively conduct two kinds of extensive work: 'cultural work' and 'social work' (Sobo 2007). Cultural work involves stigma management. They employed a variety of tactics for upholding their child's personhood and for facilitating others' understanding of their child's impairment. The parents also actively conducted extensive social work including their engagement in their child's social relationships. Facilitating their child's friendship with his/her non-disabled peers in schooling is one of these.

Given that society is designed for non-disabled people, for many of the parents of disabled children, their practices of parenting are likely to entail a battle to secure their child's safety and opportunities or to get something that they feel would improve their child's welfare. They often found out that they had to embrace a 'self-advocacy role' in order to challenge what they regarded as the injustices in their children's lives or in order to modify the environment in which their child was located.

THE PARENTS' SELF-HELP MOVEMENT AND THE POLITICS OF DISABILITY

One of the main research questions aimed to explore how the parents develop disability politics and challenge the disabling society in a collective way, especially

through working together in the form of self-help groups. The findings show that the parents' involvement in group work is firmly grounded in their experiences of disablement and daily practices as an ally of their children on the ground. Negative social attitudes towards disabled children and the absence of resources have been the prime motivators in the formation of parents' self-help groups, largely because few others than parents have as strong a reason to advocate for change on behalf of their children.

Sharing stories of suffering was an important group activity. As many of the parents testified, this greatly helped them to recover their previous experience of loneliness and isolation and contributed to them regaining a sense of empowerment. It is also an important process through which the parents free their 'silenced voices' and develop their own interpretations of the problems they face. In many aspects, their group activities prompt them to develop a collective identity beyond the conventional notions of differentiation between disabled families (such as that based on the type or degree of impairment). By reframing their unique experiences of rearing in more favourable collective and structural terms, the parents come to reinterpret their commonality from the notions of their social experiences of disablement. In working together, the parents engaged in various forms of cultural politics which challenged the deficient and pathological images imposed upon both their child and themselves. They tried to create alternative meanings in which their children's difference and their own unique experiences could be revalorised and praised. Collective advocacy was a crucial component in developing their community and facilitating the empowerment of parents. By working together, the parents come to develop a political consciousness of disability, engage in challenging

the institutional barriers and bring about social change.

FUTURE DIRECTIONS: SOME IMPLICATIONS IN THE KOREAN CONTEXT

In this concluding section, on the basis of the research findings, I discuss some salient policy and practical implications for enhancing the welfare of families with disabled children and for solving the disadvantages and exclusion that they face. I will also address some desirable future directions for the research into the disabled family within the Korean context.

Among all of the groups of parents in the study, there was a common emphasis on increasing the public awareness of disability and the need for a drive to create this. The parents consistently pointed out that the extensive exclusion and discriminatory responses to their children were caused by people's lack of understanding of their child's impairment specifically and disabled people in general. Many of the parents believed very strongly that all of those involved in delivering services should receive disability awareness training and helped to understand the perspectives of the disabled family. Therefore, it would be advisable for the state to implement this kind of training.

It has been a long-established tradition in South Korea to consider disability as a personal/family problem and, thus, securing the welfare of disabled children is taken for granted as being the parents' responsibility. Although the state has introduced some welfare policies regarding disabled people and their families during

the last decade, their emphasis remains firmly tied to the ideology of the familialisation of disability problems. In fact, except for some minimal support (for example, a 50% discount on electricity bills and tax deductions), there have not been any social security schemes designed to alleviate the problems related to caring for a disabled child. To reiterate, financial hardship is the most significant threat to families with a disabled child, and many of these families are at a great risk of poverty. It will be an the important first step for the state to introduce social security benefits designed to cover the extra costs relating to disability that has been developed in other countries, such as a 'disability allowance'. Another common disabling condition that Korean families with disabled children consistently experience is the problem of unshared care. As the parents have claimed, caring for a disabled child should not be a 'burden' that is privately born. Caring for a disabled child should receive recognition equal to work undertaken in the public sphere and the parents' contribution should be counted towards the development of inclusive citizenship. Thus, the state should has a particular obligation to support the rights of families with disabled children by providing adequate compensation for the loss of earnings or a realistic payment for the care work that the parents undertake.

In every part of Korean society, disabled children's basic human and civil rights continue to be contravened. Disabled children have been deprived of the opportunity to receive the services deemed appropriate for their development and have been excluded from participation in mainstream social activities. The parents from all groups stated that disabled children should have the same rights as non-disabled children. As they claimed, the rights of disabled children should be more forcibly enshrined in the legislation and new legislation should be introduced to help

to secure equal opportunities for disabled children, together with government sanctions against discrimination.

Undoubtedly, the politicisation of disability problems and the enhancement of the political power of disabled families are essential in order to ensure that the state provides strong support for equal opportunities and rights. During the last decade, South Korea has witnessed a burgeoning of parents' groups and political actions aiming at improving the position of disabled children and their families. This has resulted in many meaningful improvements. The further development of the parents' disability movement is necessary to continue this process of change and achieve the true inclusion of disabled children and their families in Korean society.

Research on disabled families, as knowledge production, is one of the social forces in shaping how we perceive disability problems and how the lives of disabled people and their families are understood. On the whole, the research on families with disabled children in Korea has been predominantly approached from the traditional 'stress-coping' model and concerned with 'fixing' the personal and family qualities which are identified as the barriers to adjustment. More problematically, the experiences of families with disabled children have been described in highly negative terms. It is necessary to go beyond this traditional, pathological approach and pay attention to the disabling social environments in which the families are located.

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