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**“SAME BUT DIFFERENT”: A VISUAL  
ETHNOGRAPHY OF THE EVERYDAY LIVES OF  
SIBLINGS OF AUTISTIC CHILDREN  
IN SOUTH KOREA**

**SE KWANG HWANG**

**Ph.D.**

**2009**

**“Same but Different”: A Visual Ethnography of  
The Everyday Lives of Siblings of  
Autistic Children in South Korea**

A Thesis submitted to Durham University  
for the Degree of Doctor of Philosophy

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**By**

**Se Kwang Hwang**

**School of Applied Social Sciences**

**2009**

1 2 AUG 2009



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Last, but not least, Thanks to God. You have made my life more bountiful. May your name be exalted, honoured, and glorified.

“Your young men shall see visions” (Joel, 2:28)

## ABSTRACT

This study explores the ordinary daily lives of siblings of autistic children in South Korea and draws on four theoretical perspectives: social psychological, young carers, the new sociology of childhood and cross-cultural. Building on knowledge of siblings of autistic and other disabled children in western context, I used techniques of visual ethnography to extend understanding of the everyday lives of children with autistic siblings. Nine children, aged between aged 7 and 15, in two South Korean cities were given cameras to make 'video diaries' and 'home movies' over a two week period. This was followed by reviewing sessions with the researcher to discuss the films and invitations to prepare further, age appropriate, visual representations of family life. Interviews were also held with nine mothers and two fathers to elicit their understandings of the expectations and experiences of the child participants.

Despite the modernising effects of globalisation in South Korea, the values and normative expectations of Confucian familism still provided firm foundations for family life and family expectations. Reflected by limited support from the State or voluntary organisations, the children carried important responsibilities for their autistic siblings. Important insights into their ordinary daily lives included: i) 'sacrifice' as a key part of the fulfilment of filial obligation across the life span, ii) children conceptualized their relationships with their autistic siblings as 'same but different' from those of other children; iii) the children and their autistic siblings developed '*Jeong*' (strong interpersonal ties) and '*Woori*' (togetherness) that are typical of sibling relationships in Korea, iv) high value was placed on 'harmonious family life' with significant implications for the siblings' daily lives, v) autism was integrated as part of everyday life despite experiences of stigmatising attitudes and vi) invisible vulnerabilities were reinforced by the strength of traditional expectations that discouraged consideration of the 'costs' of 'being a good sibling'.

The voices and world views of the children in this study lead to the conclusion that Confucian familist values represent a source of strength as well as challenges for the siblings of autistic children in South Korea.

# TABLE OF CONTENTS

<b>Acknowledgements</b>	I
<b>Abstract</b>	II
<b>Table of Contents</b>	III
<b>List of Tables and Figures</b>	IX
<b>Glossary</b>	XII
<b>Glossary of Korean Terms</b>	XIV
<b>Chapter 1 Introduction</b>	<b>1</b>
1.1. Purpose of the Study: Why Siblings of Disabled Children?	2
1.2. Understanding? Autism	4
1.3. Theoretical Strands	8
1.4. Outline of the Chapters	18
<b>Chapter 2 Understanding the Experiences of Siblings of Disabled Children</b>	<b>21</b>
2.1. Introduction	22
2.2. Children Affected by Sibling Disability: Social Psychological Perspectives	23
2.2.1. The Impact of Disabled Children on Their Siblings	23
2.2.1.1. Emotional Effects	23
2.2.1.2. Behavioural Effects	25
2.2.2. Variables that Influence the Impact of Disabled Children on Their Siblings	29
2.2.2.1. Sibling Variables	30
2.2.2.2. Parent Variables	33
2.2.2.3. Family Variables	35
2.2.2.4. Contextual Variables	36
2.3. Children Affected by Sibling Disability: the Young Carers' Perspective	39
2.4. Children Affected by Sibling Disability: the New Sociology of Childhood	46
2.5. Children Affected by Sibling Disability: Cross-Cultural Perspectives	49

2.5.1. A Cross-Cultural Examination at Siblings of Disabled Children	49
2.5.2. Siblings in Korean Culture	52
2.6. Conclusion and Research Questions: what we know and what we do not know	57
<b>Chapter 3 Siblings in Korean Disability Policy and Practice</b>	<b>60</b>
3.1. Introduction	61
3.2. Conceptual Understanding of Disability in Korean Culture	61
3.3. Siblings of Disabled Children in Korean Disability Policies and Legislation	63
3.3.1. The Development of Korean Welfare Disability Policies and Legislation	63
3.3.2. Siblings of Disabled children in Korean Welfare Policy and Legislation	67
3.4. Supporting Disabled Children and Their Siblings in Korea	70
3.4.1. Financial Support	70
3.4.2. Educational Support	73
3.4.3. Social Support	76
3.4.4. Supporting Siblings of Disabled Children	80
3.5. Conclusion	84
<b>Chapter 4 Research Design: visual ethnography with children</b>	<b>85</b>
4.1. Introduction	86
4.2. Methodological Issues in Past Research	86
4.3. Choosing an Appropriate Research Methodology: Visual Ethnography	90
4.3.1. Visualising Everyday Life	90
4.3.2. Visualising the Self	93
4.3.3. 'Points of Viewing'	96
4.4. Researching with Children	98
4.4.1. Children as Active Researchers	98
4.4.2. Children's Position	101
4.5. Pilot Study	102

4.5.1. Participants of the Pilot Study	103
4.5.2. Running the Pilot Study	103
4.5.3. The Pilot Study Experiences	105
4.5.3.1. Rethinking Camera Power	106
4.5.3.2. The Impact of the Camera	108
4.5.3.3. Handling Visual Data	109
4.5.3.4. Developing Research Questions	111
4.6. Field Research Setting and Data	111
4.6.1. Participants	112
4.6.1.1. Snowball Sampling	112
4.6.1.2. Sampling Procedure	113
4.6.2. Field Research Procedure	116
4.6.3. Data Collection Methods	118
4.6.3.1. The Video Diary	118
4.6.3.2. The Home Movie	123
4.6.4. Data Analysis	127
4.6.4.1. Phase One: Interpretation and Ascribing Meaning	127
4.6.4.2. Phase Two	130
4.6.4.2.1. Video Data Analysis Tool: <i>Transana</i>	130
4.6.4.2.2. Analysis	132
4.6.5. Validity: the Use of Reflexivity	136
4.6.6. Credibility	138
4.7. Ethical Considerations	139
4.7.1. Informed Consent	139
4.7.2. Privacy and Confidentiality	143
4.7.3. Gender and Age	146
4.7.4. Ensuring No Harm to Participants	148
4.8. Summary and conclusion	149

## **Chapter 5 The Meaning of Being a Sibling of an Autistic Child** **150**

5.1. Introduction	151
5.2. Snapshot from Fieldwork	151
5.2.1. Case 9 (J1) Background	152

5.2.2. Case 8 (H1) Background	153
5.3. 'Sacrifice' - Key Influential Factors	154
5.3.1. The Significance of Gender	154
5.3.2. The Significance of Birth Order	158
5.4. Disruptions to Normative Expectations related to Sacrifice	160
5.4.1. Role Reversal and Maintaining Due Respect	160
5.4.2. Disruptions to Gender related Norms	164
5.5. The Enduring Nature of 'Sacrifice'	167
5.5.1. Siblings as Caregivers	167
5.5.2. Siblings as a Financial Resource	172
5.5.3. Academic and Social Success as a Route to Social Security	174
5.6. Parents' Views	176
5.7. Summary	178

**Chapter 6 Same but Different: Children's Experiences, Perceptions and Understandings of Their Autistic Siblings** **181**

6.1. Introduction	182
6.2. Children's Perceptions of Their Autistic Siblings	182
6.2.1. Changes in the Children's Perceptions	182
6.2.2. Significant Change in Autism	185
6.3. The Children's Perceptions of Sibling Relationships	189
6.3.1. Sameness	189
6.3.2. But different	195
6.4. Cultural Understandings of Sibling Relationships	199
6.4.1. <i>Jeong</i>	199
6.4.2. <i>Woori</i>	202
6.5. Parents' Views of Sibling Relationships	207
6.6. Summary	209

**Chapter 7 Constructing 'Ordinariness' of Siblings' Everyday Lives** **211**

7.1. Introduction	212
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7.2. Seeking and Achieving Balance in Everyday Family Life	212
7.2.1. Accepting Different Parental Treatment	212
7.2.2. Accepting Second Place	215
7.2.3. Losing & Gaining in Daily Family Life	219
7.2.4. Broader Perceptions of Family Life	222
7.3. Reframing Ordinary Daily Life in the Wider Society	225
7.3.1. Living with Autism	226
7.3.2. Linking the ‘Familiar’ and the ‘Strange’	233
7.3.3. Understanding Autism	237
7.4. Parents’ Views of their Normally Developing Children’s Daily Lives in the Family and Wider Society	241
7.5. Summary	246
<b>Chapter 8 The Vulnerability of the Siblings of Autistic Children</b>	<b>248</b>
8.1. Introduction	249
8.2. Understanding the Vulnerability of the Siblings of Autistic Children	249
8.2.1. Voicelessness	249
8.2.2. Hierarchical Position	253
8.3. Other ‘Suppressive’ practices	254
8.3.1. Parental Inattention	254
8.3.2. Information	257
8.3.3. Impact on School Work	260
8.3.4. Lack of ‘Safe Personal Space’	263
8.3.5. Financial Resources	265
8.3.6. Collective Support	268
8.3.6.1. Children with Experience of Support Groups	269
8.3.6.2. Five Children’s Experiences	273
8.4. Summary	275
<b>Chapter 9 Discussion</b>	<b>277</b>
9.1. Introduction	278



9.2. Being a Sibling of an Autistic Child in a World of Confucian Familism	278
9.3. Children's Perceptions of their Autistic Siblings	284
9.4. Harmonious Family Daily Life	288
9.5. Reconstructing the Experience of Living with an Autistic Sibling in Wider Society	294
9.6. Valuing Children's Resilience and Respecting Children's Rights	298
9.7. Conclusion	305
<b>Chapter 10 Conclusion</b>	<b>308</b>
10.1. Introduction	309
10.2. Summary of the Main Findings and Theoretical Implications	309
10.3. Contributions of This Thesis	313
10.4. Implications for Korean Policy and Practice	314
10.4.1. Invisibility within the Social Support System	314
10.4.2. Assessment Focus on Problems not Needs	317
10.4.3. Adult-Centred, Supply-Led System	320
10.4.4. Summary of Implications for Korean Policy and Practice	322
10.5. Agenda for Future Research	323
10.5.1. Implications of Limitations of the Study	323
10.5.2. Implications for Future Research	325
10.6. Final Remarks	327
<b>Bibliography</b>	<b>339</b>
<b>Appendices</b>	<b>394</b>
Appendix A Information Packages	395
Appendix B Field Research Time Schedule	401
Appendix C Interviews with Parents: Topic Guide	403
Appendix D Brief Summary of Video diaries and Home movies content and context	405
Appendix E Analysis, Coding and <i>Transana</i> (version 2.10)	407
Appendix F Guide to Romanization	409
Appendix G Keywords Networks	411
Appendix H The Process of Back-Translation from Korean to English	413
Appendix I Ethical Approvals	414

# LIST OF TABLES AND FIGURES

## **Tables**

Table 1-1	Classification for the Diagnosis of Autism in Korea	7
Table 1-2	The Estimated Number of Autistic People in Korea	7
Table 1-3	Models of Disability	14
Table 2-1	Evidence of the Emotional and Behavioural Effects on Siblings of Living with Autistic or Other Disabled Children	29
Table 2-2	A Comparison of Sibling relationships in South Asia and North America	49
Table 3-1	Korean Legislations with Relevance for Disabled Children	67
Table 3-2	The Estimated Number of Disabled People in Korea	77
Table 3-3	Example of Types of Sibling Support Groups	82
Table 4-1	Example of Measures & Methods of Previous Studies	88
Table 4-2	Characteristics of the Participants	115
Table 4-3	Field Research Process	117
Table 4-4	Example of Video Diary Structure	120
Table 4-5	Example of Keywords Drawn from (Four) Different Sources of Data Relating to the Same Case	135
Table 9-1	Disabled People (all ages) who Live with Caregivers in the Same Household	283
Table 9-2	Disabled People (all ages) Requiring On-going Assistance from Family Members Living in the Same Household	283

## **Figures**

Figure 1-1	Socio-cultural Perspective of the Experience of Being a Sibling of an Autistic Child	10
Figure 2-1	Illustration of Influencing Variables	30
Figure 2-2	Contextual Variables Influencing Siblings of Disabled Children	37
Figure 2-3	The Development of Social Psychological Studies focussing on	

Siblings of Disabled Children	39
Figure 2-4 Model of extended Korean family (left) and nuclear Korean family (right)	53
Figure 2-5 The Relationships between Structure and Expression, and Function of <i>Jeong</i>	55
Figure 2-6 Model of Korean Sibling Relationships	56
Figure 3-1 Basic Framework for Disability Policy in Korea (2003-2007)	66
Figure 3-2 Percentage of Disabled Children Attending Formal Educational Facilities	73
Figure 3-3 Percentage of Disabled Children Attending Informal Educational Facilities	73
Figure 4-1 Pilot Study Design	102
Figure 4-2 Conceptualizing the Diarist's Gaze	120
Figure 4-3 Watching Baseball Game while Taking Video Diary	122
Figure 4-4 Facial Expression (Suggesting Irritation) towards Mother	122
Figure 4-5 Playing Computer	125
Figure 4-6 Cutting Hair	125
Figure 4-7 J2's Homework	126
Figure 4-8 Sleeping with Mother	126
Figure 4-9 Transana Screen Capture Showing (from top left) the waveform of the audio, the video frame, the transcript and the coding frame.	130
Figure 4-10 Source from Case 6 home movie-8	133
Figure 4-11 Source from Case 2 home movie-2	133
Figure 4-12 Triangulation Involving Multiple Data Sources and Methods	138
Figure 5-1 'Fish in the net' drawing by F1	163
Figure 5-2 Shopping with Autistic Sibling	168
Figure 5-3 Outing with Autistic Sibling	169
Figure 5-4 Playing with Autistic Sibling	169
Figure 5-5 Eating Pear	170
Figure 5-6 Spider-Web 'People in My Family'	171
Figure 5-7 Studying at Late Night	176
Figure 6-1 J2 washing & brushing teeth under direction of J1	186
Figure 6-2 H2 preparing bed under direction of H1	187
Figure 6-3 Physical Fighting between Siblings	194
Figure 6-4 J2's Tantrum and Buying a snack	196

Figure 6-5 Spider-Web ‘People in My Family’	198
Figure 6-6 J1’s Own Room (up) and Bedroom (next page)	203
Figure 6-7 H1 and H2’s Room	204
Figure 6-8 J2’s Erratic Sleep Disturbance	205
Figure 7-1 Mother and J2 doing Homework	213
Figure 7-2 Mother cooking and looking after J2	213
Figure 7-3 D1 draws that her family is going to amusement park	220
Figure 7-4 Dinner with Extended Family at Korean Traditional Restaurant.	222
Figure 7-5 Injured Toe	224
Figure 7-6 Injured Ear	224
Figure 7-7 Walking with Parents	227
Figure 7-8 Shopping with Family	231
Figure 7-9 A2 Cleaning Living Room	238
Figure 8-1 Life Timelines of Children and their Autistic Siblings	254
Figure 8-2 Homework	261
Figure 9-1 Model of Relationships between Children and Their Autistic Siblings	285
Figure 9-2 Model of the Influence of Cultural Values on the Identities and Daily Lives of Siblings of Autistic Children	307
Figure 10-1 Diagnostic Assessment Procedure for Autism in Korea	318

## GLOSSARY

**Autism:** This term is used in this thesis to describe any ‘autistic spectrum disorder’.

**Autistic Child:** Throughout this thesis, the phrase ‘autistic child’ is used rather than ‘child with autism’. There are debates about appropriate terminology (e.g. Marks, 1997, Mihaylov *et al.* 2004). The term, ‘autistic child’ will be used because the phrase ‘child with autism’, implies that the resulting disability is something intrinsic to the child (Colver, 2005).

**Confucian Familism:** East Asian societies have a ‘familist worldview’ (Hui, 2008). Individuals take their values from the collective values of the family. Koreans depend on their own families (even extended family) for their identities, financial, physical, emotional and spiritual needs. Traditionally, familism has been attributed to (Neo-) Confucianism in Korea (Park, T.H., 2004). Neo-Confucianism combines the social ethics of the classical Chinese philosophers Confucius (Kong Zi, 551-479 B.C.) and Mencius (Meng Zi, 372-289 B.C.) with Daoist, or Taoist, and Buddhist metaphysics (Keum, 2000). In particular, Confucianism emphasises the importance of family life for personal cultivation and social ordering based on the values of strong familism, such as family ties, filial piety and family discipline through submission, obedience, sacrifice and loyalty to the patriarchal authority (Kim, E.H. 1998; Sung, K.T., 1998a, b; Keum, 2000; Hahm, 2003).

**CDAs:** Child Development Accounts

**CCCDs:** Community Care Centres for Disabled People

**DOH:** Department of Health

**Filial Obligation:** Under Confucian familism filial piety is highly valued and associated with, filial obligation (or responsibility) that has been institutionalised over a long period time in Korea.

Filial obligation refers to filial duty that children should provide care or support for their parents and other family members requiring support (see e.g. Lee & Sung, 1998; Fuligni *et al.*, 1999; Fuligni & Zhang, 2004). This obligation includes practical care, financial contribution, and extends into adulthood.

**IFSP:** Individual Family Support Plans

**KCCR:** The Korea Council for Children's Rights

**KNSO:** Korea National Statistical Office

**KOCCO:** Korea Council of Children's Organisations

**MOEHR:** Ministry of Education and Human resources

**MOHW:** Ministry of Health and Welfare

**MOGEF:** Ministry Gender Equality & Family

**MOL:** Ministry of Labour

**NHRCK:** National Human Rights Commission of Korea

**NIASA:** National Initiative Autism: screening and assessment

**Siblings:** In this thesis, the siblings who are participants in this study are all biological brothers or sisters, and have the same parents as their autistic siblings. None of the participant siblings was disabled.

**PMP:** Personal (Portable) Multimedia Play/Recorder

**Sacrifice** (Korean *huisaeng*): The Korean term *huisaeng* means an act of contributing or giving up individual life, finances, honour, benefits for the sake of someone or something that is of greater value or importance (Standard Korean Language Dictionary, 1999). In Confucian familism, dominant collectivism provides the rationale for sacrifice to the family in which physical and financial sacrifice are strongly valued (e.g. Suzuki & Greenfield, 2002). In particular, the needs of the family have priority, and each family member is expected to subordinate personal needs and desires to the well being of the whole family.

**UNCRC:** United Nations Convention on the Rights of the Child 1989

**WCCDP:** the Welfare Coordination Committee for Disabled Persons

## Glossary of Korean Terms

- Chapae:*** Autism
- Chemyeon:*** Losing face
- Do-Ho-Bu-Chung-Sa:*** A Name of Historical Heritage.
- Hakwon:*** Private Educational Institute
- Ijil:*** Differentiation
- Jangae(in):*** Disability (disabled people)
- Jeong:*** Strong interpersonal ties
- Jjockpalida:*** A Slang expression used by young people to mean losing face
- Gongbu-bang:*** One of Private Educational institute
- Nori-bang:*** Private Children Day Care Centre
- Pachulbu:*** Housework assistant
- Woori:*** We or us
- Ya-gan-ja-weul-hak-seup or Yaja:*** Extra study in school at night

## Chapter One

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### Introduction

---

*Autism is a terrible, life long disorder, but it's a better time than ever to be autistic.*

(Grinker, 2007:6)

*I saw myself holding my brother David's hand, leading him through his days, big emptiness all around me.*

(Karasik & Karasik, 2003:4)



## 1.1. Purpose of the Study: Why Siblings of Disabled Children?

Siblings are among those with whom we have the closest and most long-standing relationships in life. And growing up as members of the same family creates opportunities to form unique relationships regardless of ability or disability (e.g. Cicirelli, 1995; Brody, 1998; Dunn, 2000, 2004, 2005; Volling, 2003; Akhtar & Kramer, 2004; Sanders, 2004; Oliva & Arranze, 2005; Pike *et al.*, 2005). Siblinghood has long been written about, for example the Old Testament offers accounts of great rivalry, jealousy, adjustment, bereavement, bullying and co-operation between brothers or sisters (e.g. Esau and Jacob, Joseph and his brothers).

Since the 1950s, research has reflected increasing interest in the impact of disability and chronic illness among children on families, especially parents (see e.g. Dyson, 1997; Randall & Parker, 1999; Trute & Hiebert-Murphy, 2002; Hasting *et al.*, 2006; Knott *et al.*, 2006) and their siblings (e.g. Kaplan, 1969; Grossman, 1972; Gath, 1974; Lavigne & Ryan, 1979; Simeonsson & McHale, 1981; Breslau, 1982, 1983; Ferrari, 1984; McHale *et al.*, 1984, 1986; McHale & Gamble, 1989; Gamble & McHale, 1989; Lobato *et al.*, 1987; Dyson, 1989; Wilson, 1989; Lobato, 1990). In spite of this growing interest there has been very little empirical research on the experiences of siblings of disabled children, a subject that has received only limited attention. For instance, the identities of siblings of disabled children remain largely unexplored (Banks *et al.*, 2001:801) and methods for exploring their perspectives and everyday experiences remain underdeveloped. This lack of empirical attention is reflected in the limited knowledge and theory available for understanding the worlds of siblings of disabled children (Stoneman, 2005). There are notable gaps in the exploration of siblings' experiences **from their own perspectives** (e.g. Connors & Stalker, 2003; Edwards *et al.*, 2005; 2006). In this thesis, therefore, my goal is to add to knowledge by supporting children to explore, present and reflect upon their own experiences as siblings of autistic children in ordinary daily life in their family and wider society. My study is based in South Korea (hereinafter Korea), the country and culture within which I was brought up. My interest in the experiences of siblings of autistic children stems from my professional experience as the Director of a Christian day care and special education

centre for disabled children<sup>1</sup>. My contact with the siblings of the disabled children indicated that they felt a sense of neglect in so far as little interest was shown in their experiences of daily life. Reading of the literature confirmed their sense of neglect.

In 2005, 4.59% of the Korean population was defined as 'disabled' (Byun *et al.*, 2006a:157) reflecting a narrow view of disability as experience of a limited number of specific conditions (see Yoo, H.J., 2005). 98% of disabled people live in their communities but 2% stay in long-term care facilities. Traditionally, disability has been associated with family shame, social stigma, discrimination and exclusion. Processes of modernization and globalization have brought influences from Western cultures (see Yim, H.S., 2002), and disability welfare policies have been introduced and developed<sup>2</sup> (see overall review Kim & Ross, 2008). However disability retains its position as a sign of dishonour and shame linked to stigma, discrimination and exclusion (Choi & Lam, 2001:81; NHRCK, 2002; Won *et al.*, 2004:148; Kim-Rupnow, 2001:15, 2005; Kim & Min, 2006:406). Disabled people are treated as second-class citizens rather than people with rights to be included in the mainstream of society (Kim & Davis, 2006:417). The major part of Korean research in the field of disability has neglected the issue of siblings of disabled children, despite acknowledgement of the impact of children's disabilities on families (Chung *et al.*, 2003; Choi, M.S., 2003; Lee, W.S., 2004; Sung *et al.*, 2005).

Most existing studies of siblings of disabled (including autistic) or chronically ill children focus on Western experience, with very limited studies from non-Western cultures (e.g. Marciano & Scheuer, 2005). Such limitations may reflect a lack of awareness of cultural issues and of ways that those issues affect autistic children and their families. Autistic children do not exist in isolation, being affected by their socio-cultural worlds. Similarly, the siblings of autistic children are affected by the socio-cultural context in which they relate to their disabled siblings on a daily basis (see Cuskelly, 1999:120; Hodapp *et al.*, 2005:337). My argument is that the everyday lives of siblings of autistic children are characterized by complex sets of experiences and

---

<sup>1</sup> Confucian practice still persist in Korean thought and life, and it also exists in combination with modern Korean Christianity (Kim, Y.G., 2002), although Christianity grafted Western thought to traditional Korean thought (Park, W. 2006:124).

<sup>2</sup> see overall review of current welfare policy development and debates in Korea, Lee, H.K.(2005), Ahn & Lee (2005), Kim, Y.M. (2006, 2008)

relationships within, and outside, the family that are affected directly or indirectly not only by their siblings' disability but also by social and public attitudes to disability. In this study I aim to provide a platform for siblings of autistic children to give (oral and visual) expression to their experiences, their pleasures and concerns, their opportunities and challenges. In this way I aim to offer a new understanding about the experience of being the brother or sister of an autistic child from their own perspectives; how autism affects their daily lives, and whether it makes their experiences different from children whose siblings are not disabled.

## 1.2. Understanding? Autism

Although autism is a widely recognized disorder, its true prevalence is not known and its precise causes still not understood (e.g. Rutter, 1999, 2005a; Lewis, 2003). The term 'autism' was firstly introduced by Bleuler in 1911. The words 'autism' and 'autistic' come from the Greek *autos*, meaning 'self' and 'ism' which implies 'orientation or state' (Frith, 2003:5; Trevarthen *et al.*, 1998:5). According to Kleinman *et al.*, (2008:606), the average age at which caregivers first express concern about their children to a doctor is 17 months, but the average age of diagnosis of autism is significantly later, often as late as 4 years or even older. Recent studies have reported that autism can be detected in children under 3 years old (Baird *et al.*, 2001; Charman & Baird, 2002). However, screening and diagnostic instruments for autism in children are still relatively underdeveloped and there is no consensus about the most accurate methods for diagnosing autism (Bristol-Power & Spinella, 1999; Robins *et al.*, 2001; NIASA<sup>3</sup>, 2003; Williams & Brayne, 2006; Eaves *et al.*, 2006).

Clinically, definitions and diagnoses of autism have changed continually since Kanner's identification of autism in 1943. Internationally recognized manuals such as the *Diagnostic and Statistical Manual of Mental Disorders* (4<sup>th</sup> Ed.) (DSM-IV) (American Psychiatric Association, 2000) and the International Classification of Diseases-10 (ICD-10) (WHO, 2003) provide broad criteria for the recognition of autism within a spectrum from low functioning (e.g. classical Kanner syndrome) to high functioning, Asperger's

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<sup>3</sup> National Initiative for Autism: Screening and Assessment

syndrome, and pervasive developmental disorders not otherwise specified that comprise one or several specific abnormalities. All criteria for autism have focused on core deficits in common areas such as language ability, social behaviour, cognitive and neuropsychological abilities, and psychiatric health, because no specific biological markers are known (see Hill & Frith, 2003).

Despite the international diagnostic criteria, autism still remains a complex and mystifying disability and there is ongoing debate over whether categorical or dimensional conceptualizations are more appropriate (e.g. Gillham *et al.*, 2000; Klin *et al.*, 2000; Freeman *et al.*, 2002; Leekam *et al.*, 2002). NIASA (2003:16) oppose the simple categorization of individuals within the boundaries of specific syndromes and question the nosological validity of the sub categories within ICD-10 and DSM-IV in considering the conceptualization of autism. They argue the importance of considering both diagnosis and the identification of special needs when developing guidelines for 'autistic' individuals. The difficulty of identifying autism as a single condition (Dempsey & Foreman, 2001) raises the question as to whether autism is one type of disorder or several similar types with different conditions. Furthermore, autism is frequently associated with other disorders such as attention deficit disorder, lack of motor coordination and psychiatric symptoms (Hill & Frith, 2003:281). The internationally recognized diagnostic systems have also been criticized on the grounds that their heavy reliance on categorical approaches to defining autism (Gillham *et al.*, 2000:269) has resulted in confusion, despite widespread agreement about the central features of autism. For example, categorical definitions of autism have failed to consider criteria within a developmental perspective, and may be confusing to parents and professionals alike. Prior (2003:81) comments that:

This leaves plenty of latitude for researchers and clinicians to make varying interpretations from their diagnostic assessments, and it greatly widens the capacity to accept children with social, cognitive and behavioural problems and what might have been called 'eccentricity' in former times, as being 'on the spectrum'.

Klin *et al* (2000:163) argue that there are no biological markers in the identification of autism and it remains impossible to identify autism through one factor (Howlin,

2002:54) with diagnostic practices still reliant on developmental history and behavioural observations made by clinicians. In short, autism is poorly understood and has mystified professionals for more than half a century. This diagnostic confusion can lead families to seek unhelpful therapies.

While understanding of autism continues to present significant challenges, the incidence of diagnosed autism has risen dramatically over the last thirty years with improved recognition of a broadening set of diagnostic criteria (Fombonne, 2003; Prior, 2003; Rutter, 2005b). Recent studies in different parts of the world suggest that the overall prevalence rate is between 40 and 60 per 10,000 (Baird *et al.*, 2000; Powell *et al.*, 2000; Bertrand *et al.*, 2001). In England, for example, Chakrabarti & Fombonne (2001) estimated that autism affects 62.6 per 10,000 children under 8 years old.

Numerous reports have been published on autism research, but few have examined international perspectives (see e.g. Won *et al.*, 2004; Dyches *et al.*, 2004; Grinker, 2007; Nehring, 2007). Mesibov *et al.*, (2005) have argued that autism represents a culture in its own right:

Autism too, however, affects the ways that individuals think, eat, dress, work, spend leisure time, understand their world, communicate, etc., and people with autism tend to be devalued because of their difference. So, in a sense, autism can be thought of as a culture, in that it yields characteristic and predictable patterns of thinking and behaviour in individuals with this condition (p.19).

In Korea, the word for autism is '*Chapae*', derived from Chinese written characters. It means literally 'being closed in on one's self' (Grinker, 2007:237). In this respect, autism is often described as 'being absorbed in him/herself', or 'completely wrapped up in him/herself' with little interest in other children or in social chat or activities. But this description misses many other features of autistic children's behaviour. The Korean movie 'Maraton'<sup>4</sup>, very popular in 2005, is based on the true story of an autistic young person who was a skilled marathon runner. It had a profound effect on autism awareness in Korea, where there is so much stigma associated with mental disorders that autism,

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<sup>4</sup> pronounced the way the main character (autistic young person) says the word 'Marathon'

commonly confused with mental disorder, is often kept secret (see Donnelly, 2001:296). The term 'autism' is well known in Korea today. Autism has been officially categorized as a disability since 2000. Before 2000, autistic people were categorized as 'mentally retarded'. Korean criteria for the diagnosis of autism make use of the ICD-10 and autism has defined disability grades according to type and severity (see Table 1-1).

**Table 1-1** Classification for the Diagnosis of Autism in Korea

Grade	Diagnosis Criteria of Deficits
1 <sup>st</sup>	According to the diagnosis of ICD-10, a type of pervasive developmental disorder (autism) that is defined by: presence of abnormal or impaired development, IQ grade under 70, the characteristic type of abnormal functioning and behaviour in all the 12 of 20 areas, GAS point under 20
2 <sup>nd</sup>	According to the diagnosis of ICD-10, a type of pervasive developmental disorder (autism) that is defined by: presence of abnormal or impaired development, IQ grade under 70, the characteristic type of abnormal functioning and behaviour in all the 8 of 20 areas, GAS point under 21-40
3 <sup>rd</sup>	According to the diagnosis of ICD-10, a type of pervasive developmental disorder (autism) that is defined by: presence of abnormal or impaired development, IQ grade over 71, the characteristic type of abnormal functioning and behaviour in all the 4 of 20 areas, GAS point under 41-50

(Cited from MOHW (2005) *Welfare of Disabled Persons Act*. p.272)

There has been no national prevalence study of autism in Korea. The first nation-wider research on disabled children using criteria of DSM-IV indicated that a prevalence of autism in children aged 6 to 11 was estimated at 5.54% (Lee, S.H. 2002:46). According to Byun *et al.*, (2006a:163) using criteria of ICD-10, however, the prevalence of autism in children under 18 was estimated at 0.17%.<sup>5</sup> Korea was estimated to have a total of 33,671 autistic (pervasive developmentally disorders) people in the population at the end of December 2005 (see Table 1-2).

**Table 1-2** The Estimated Number of Autistic People in Korea

	Male	Female	Total
Estimated number of autistic people	26,967	6,704	33,671

(Source: Byun *et al.*, (2006a) 2005 *National survey on People with Disabilities*. p.387)

<sup>5</sup> The estimated number of autistic children under aged 17 was 19,106. The estimated prevalence of autism was 0.05% in the population (Byun *et al.*, 2006a: 163-164).

Interestingly, the national survey of disabled people shows a significant increase in the number of registered autistic people from 1,190 in 2000 to 18,841 in 2005 (Byun *et al.*, 2001; 2006a). However, according to national survey (Byun *et al.*, 2006a:387), there are no data for those aged over 40. For this, and other reasons discussed above, the prevalence of autism in Korea remains unknown.

Autism cannot be understood through one snapshot (Frith, 2003:1). Autism manifests differently according to cognitive or behavioural development and will look different at different ages. Dramatically, certain symptoms can appear or disappear with time. In summary, it is very complicated, if not impossible, to define autism in a context where the condition is poorly understood, and where the diagnostic criteria have been broadened. What is clear, however, is that awareness of autism is increasing (even if negatively) and more people than ever are now diagnosed as autistic.

### 1.3. Theoretical Strands

This study will take a socio-cultural approach drawing on three theoretical strands: social constructionism, children's rights and the cultural model of disability.

Socio-cultural theory has been heavily influenced by the work of Vygotsky (1962) as well as Neo-Vygotskians (Moll, 1990; Rogoff, 1990; Tharp & Gallimore, 1988). Vygotsky's main argument lies in the understanding of human cognition and learning as social and cultural rather than individual phenomena. Children experience particular patterns of thinking and communicating in interactions with more competent members (parents, siblings, or peers) of their culture (Rogoff, 1990). In this way, children adopt cultural norms that in turn shape their attitudes, beliefs, values, and understanding of daily experiences such as communication, religion, food, family rituals. Socio-cultural theory emphasizes the importance of understanding people within their own culture which strongly influences behaviour and interactions (see Cooper, 1999; Rogoff, 2003; Weisner, 2002; Berry, 2004; Georgas *et al.*, 2004). Cultural knowledge serves both to guide the behaviour and actions of cultural members and to support the interpretation of experiences by outsiders (Donnelly, 2001:293).

In this respect, the definitions and essential experiences of ‘being’ a sibling may differ in different societies and cultures where different historical, linguistic, socio-political, and psychological perspectives prevail (see Weisner, 1993a; Cicirelli, 1994). The concept of ‘sibling’ may be complex, identified by biological/genealogical criteria, legal criteria or extension of kinship through blood ties. Even where siblings share common environments across a life time, their experiences can vary within environments (Daniels & Plomin, 1985; Dunn & Plomin, 1990; Deater-Deckard *et al.*, 2001), emphasizing the importance of acknowledging “those environmental factors that work to make siblings in the same family different from one another rather than similar” (Pike *et al.*, 2000:96). The daily lives of siblings are shaped by cultural context so that differences across cultures and countries can provide important information relevant to the experiences of children growing up with autistic siblings. Their experiences are very complex and ‘not unidimensional’ (Powell & Gallagher, 2005:12). As Lobato *et al.*, (2005:625) have argued:

One would expect that children growing up in a culture that bestows significant value to the sibling relationship would respond differently to a brother’s or sister’s disability than children raised in a culture in which sibling relationships are secondary even to friendships.

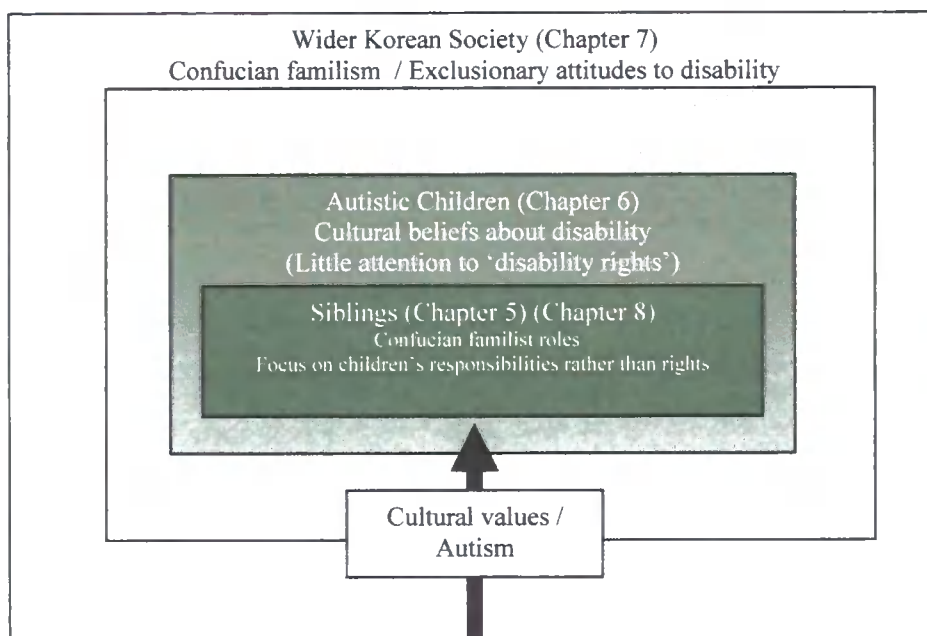
In order to gain an understanding of the everyday lives of children living with autistic siblings, it is vital to draw on knowledge of the cultural norms, values and beliefs that give meaning to, and provide a context for, interpreting their daily life experiences (see Greenfield *et al.*, 2003:464-465).

In this thesis, the socio-cultural perspective is represented by embedded layers, representing a larger cultural context (Figure 1-1) with the siblings of autistic children at the centre. The large outer system represents the socio-cultural norms and values of wider society. The two intermediate systems represent the environmental context of the family (parents and siblings) and the immediate environment that is heavily influenced by the interpersonal relationship with the autistic sibling. Each of these systems informs and is informed by cultural values relating to disability in general and autism in particular so that the experiences of the siblings are influenced by social attitudes to



disability and autism mediated through: i) family responses and different degrees of achieving a harmonious family life and ii) the experiences and responses of the autistic sibling.

**Figure 1-1** Socio-Cultural Perspective of the Experience of being a Sibling of an Autistic Child



In this thesis, the term of 'socio-cultural perspective' makes use of Korean concepts, derived from Confucian familist socio-cultural beliefs, attitudes and values.

Culture is not static or given, rather people change as they participate in their own cultures, and culture changes in response to people (Rogoff, 2003). Culture is interpreted and created through daily interactions between individuals and their social surroundings (Berry & Poortinga., 2006:53). From a social constructionist perspective, social reality is not a product, but it can be constituted by the interaction between meaning and contexts according to time and culture (Berger & Luckmann, 1967). Meaning is constantly modified according to context so that the interaction between context and culture produces new meanings and new understandings. Social constructionism pays particular attention to the construction of reality and a sense of self related to various phenomena such as gender, class, ability or culture, through seeing/hearing the world and reflecting it back in accounts of personal and wider social

experience. Social constructionism suggests that people create or re-create socially diverse meanings and understandings of thought and behaviour through everyday lives. Edwards *et al.* (2006:9) argue that people interact and build diverse meaning and understanding from specific social and geographical locations, ethnicity, social class, age, gender and so on, so that they are themselves socially constructed. Applying this argument to children, they are usefully seen as competent informants about, and interpreters of, their own lives and of the lives of others (James, 2001).

In exploring the daily lives of siblings of autistic children I start from the position that the siblings are competent to reflect or reframe their thoughts and experiences of autism, their everyday family and social lives with their autistic siblings. In particular, I employ the device of 'linking the familiar and the strange' drawn from Foucault's 'familiar and poorly known horizon' (Foucault, 1997:144) to challenge the status of knowledge as 'taken-for-granted' and to achieve the status of insider's truth – in this case the truths of children living with autistic siblings. I shift away from the familiar researcher's gaze (as a fellow Korean) in order to move towards the children's perspectives and reveal insights about their 'strange' worlds.

A second theoretical strand is drawn from the children's rights perspective. Although siblings of disabled children are not the only vulnerable children in society, their voices have been 'muted' (Naylor & Prescott, 2004:200). The relative value of 'hearing' these hidden voices varies in different cultures, reflecting the different value of children and changing attitudes to childhood (e.g. Flekkøy & Kaufman, 1997; Tao & Drover, 1997; Woodhead, 1997). Despite different cultural positions and perceptions of children internationally children's rights, based on the United Nation Convention on the Rights of the Child 1989 (hereinafter UNCRC) (UN, 1989),<sup>6</sup> are heavily informed by Western perspectives (e.g. Burr, 2004; Suaalii & Mavoia, 2001) and make common provisions for all children (Smith, 1997).

However, there are critical discussions between 'rights-based' and 'needs-based' approaches to the welfare of children. Cornwall & Nyamu-Musembi (2004) argue that:

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<sup>6</sup> Korea ratified the UNCRC in 1991

.....whereas a needs-based approach focuses on securing additional resources for delivery of services to particular groups, a rights-based approach calls for existing resources to be shared more equally and for assisting marginalized people to assert their rights to those resources. It thus makes the process of development explicitly political. (p.1417)

Furthermore, Woodhead (1997) warns of the danger of framing children's 'rights' within a needs-based framework; where 'needs' are typically constructed by adults ignoring children's autonomy and self-determination. Similarly, frameworks based on 'the best interests of the child', fail to embrace alternative political, economical, religious and cultural constructions of 'needs' and 'rights'. Smith (2007) has argued that rights, unlike needs, are acknowledged as cultural constructions of essential entitlements for children, one explanation for why the universal notion of children's rights has not succeeded in preventing the exclusion of many children from the processes of protection, participation and consultation that form the central aspiration of the UNCRC (e.g. Freeman, 2000). In this respect, a children's rights perspective offers powerful support to the principle of hearing the voices of children as they are empowered to participate in the process of defining their own vulnerabilities.

Growing awareness of children's rights has led to a heightened awareness of the rights of disabled children. Researchers have argued that disabled children want to be seen as 'normal', though different (Priestley *et al.*, 1999). As articulated in the new sociology of childhood perspective, disabled children wish to be seen as active agents defined by their abilities, and actively resist identities as disabled. Nevertheless, disabled children are likely to be subjected to a deficit model and the identification, by others, of their 'special needs' throughout their development. One implication of the focus on 'special needs' of disabled children is that the needs and rights of their non-disabled siblings are easily obfuscated as adults within the family focus primarily on the needs of the disabled child.

The marginalised recognition of the rights of non-disabled siblings is central to their construction as 'young carers', discussed more fully in section 2.3. (e.g. Aldridge & Wates, 2005). But at this point, I simply wish to argue that, in the Korean cultural context (see section 2.5.2) in which family relations are characterised by strict

hierarchical interpersonal relationships, siblings of disabled children face additional challenges in articulating their needs.

The UNCRC outlines the substantive right of **all** children to have their views heard. And Burke (2004:75), writing about families with disabled children in an English context, argues that ‘the needs of siblings should be considered equally with those of others in the family. The right to express feelings must be recognised for all children’. There is little empirical research focusing on the voices of siblings of disabled children (e.g. Connors & Stalker, 2003; Burke, 2006), and research in Western contexts demonstrates significant methodological challenges (for review Cuskelly, 1999). I argue that these challenges are accentuated in societies, such as Korea, that are characterised by hierarchical family relationships. Therefore, I argue that adopting a rights-based approach may help to illuminate the socio cultural mechanisms that create and maintain children’s silence and to identify possible opportunities for ‘giving voice’ to Korean siblings of autistic children (see figure 1-1).

The third theoretical strand, the cultural model of disability, is consistent with contemporary developments in thinking about and theorizing disability. Three principal models have influenced modern thinking about disability: medical, social, and cultural (see Table 1-3).

According to Table 1-3, a central focus of the medical model of disability lies in the location of disability as an individual problem tied to the functional limitations of bodies (Swain *et al.*, 2003:22). The medical model of disability can contribute to the development of: i) understanding the causes of impairment, ii) medical resolutions and iii) rehabilitation processes. But this model also defines disability as inadequacy and with attention focused on the impairment rather than the needs of the person (Crow, 1996), can lead to restricted living arrangements and social isolation. At its most extreme, the medical model creates insurmountable barriers of negative stereotypes of disability that result in dependency and exclusion.

**Table 1-3** Models of Disability

<b>Medical Model of Disability</b>	<b>Social Model of Disability</b>	<b>Cultural Model of Disability</b>
Disability is an individual problem	Disability is a problem in society	Disability is constructed culturally
Differences in abilities are inadequacies	Differences in abilities are assets	Differences in abilities are accepted without judgement, and associated with empowerment and pride
Seeing deficits	Seeing strengths	Seeing variety
Special service provision	Accessible mainstream services	Culturally appropriate services
Society choosing for 'them'	Disabled people choosing for Themselves	Disabled people develop identity rather than rejecting it
Charity model	Rights model	Conceptual/practical/ethical model
Patient	Citizen	A state of being
Institution orientated	Community orientated	Socio-cultural orientated
Exclusion	Inclusion	Variety-inclusive

(Source from Devlieger (2005) *Generating a cultural model of disability*)

The medical model has been challenged by disabled people who have developed the social model of disability in which disability is defined as social oppression, and a distinction is drawn between disability and impairment (Oliver, 1990; 1996; Barnes & Mercer, 2003; Thomas, 2004). The central tenet of the social model is that disabled people experience social exclusion as the result of physical, environmental, legal, cultural and attitudinal barriers that amount to social oppression and deny disabled people the same opportunities available to non-disabled people (Swain *et al.*, 2003:24). Proponents of the social model oppose the view of disability as 'tragedy' and stress the potential for positive personal and collective disabled identities (Swain & French, 2000:571), arguing for equality of rights and citizenship (see for review Tregaskis, 2002). The social model marked a significant shift in thinking about disability and has led, in some parts of the world, to changes in legislation, policy and practice that go some way to providing equal opportunities for disabled people. However, critics (see Shakespeare & Watson, 2001) argue that the social model fails to address the reality of the lived experience of impairment. A further critique of the social model (e.g. Ahmad 2000:2) is that its focus on loss of independence and, lack of control over resources is perceived as being over-Westernized by many for whom interdependence, mutual support and reciprocity are the hallmarks of social and family relationships. This describes the socio-cultural context in Korea, informed by its Confucian familist values and norms. As Ahmad (2002) argues, people from non-Western societies also face

discrimination, but their marginalization must be understood in terms of ‘what is considered ‘normal’ for someone of their gender, age and class in their own culture’

The most recent development in theorizing disability is the emergence of a cultural model in which disability is a natural part of life (Gilson & Depoy, 2000; Brown, 2002; Conyers, 2003), and disability is defined as a cultural construct (Ingstad & Whyte, 1995; Priestley, 2001; Gilson & Depoy, 2000; O’Hara, 2003; Daley, 2002; Cho, Y.T., 2004; Devlieger *et al.*, 2007; Welterlin & LaRue, 2007). The social model determines that disability is the product of social oppression and social exclusion, whereas the cultural model understands disability as inherent within the socio cultural system itself (Cason, 2007:31). Snyder & Mitchell (2006:9-10) argue that the cultural model provides a fuller concept of disability and impairment than the social model:

The term *disability* recognizes that there exists a necessary distance between dominant cultural perspectives of disability (sometimes signified as ‘handicap’) as tragic embodiment and a politically informed disability-subculture perspective that seeks to define itself again devaluing mainstream views of disability. .... the cultural model has an understanding that impairment is both human variation encountering environmental obstacles and socially mediated difference that lends group identity and phenomenological perspective.

Disability is characterised as “same but different” (Devlieger *et al.*, 2003:10). Gilson & Depoy (2000:211) argued that disability identity can be internally derived or externally imposed depending on how disability is viewed within specific cultures. Disability is “set of social relations” (Davis, 1995:11). The cultural model emphasizes respect for the different lives of disabled people. The cultural model emphasizes the social value of disabled people rather than their impairments and disabling conditions. In the cultural model, disability is viewed as part of the construction of society itself rather than simply the result of social discrimination. The cultural model, with emphasis on diversity and complexity, has highlighted the differences in the interpretations of disability that exist between and within cultures (Gilson & Depoy, 2000; Rao, 2006). Differing cultural understandings of, and attitudes to, different impairments also lead to variations in experiences of social inclusion and exclusion.

Despite a wealth of research about the neurological basis of autism (e.g. Akshoomoff *et al.*, 2002; Mundy, 2003; Williams *et al.*, 2006) there is little attention to the application of different models of disability to autism in the literature. The predominance of medical research, however, suggests a popular belief that the ‘problem’ lies in the individual. Three characteristics commonly associated with autism: communication difficulties, social understanding and cognitive ability (Hill & Frith, 2003) further reinforce the assumption that autism can best be understood in terms of the medical model of disability and interventions are typically aimed at reducing challenging behaviours of the autistic individual (Smith, 2006). The social model of disability has yet to make any substantial impact on contemporary Western understandings of autism (Saner, 2007). Although there is recognition of the high level abilities of some individuals (known as ‘high functioning’) who have been diagnosed with autism, they continue to be perceived as ‘different’ (Baron-Cohen, 2000). In contrast, the cultural model of disability perceives autism as a naturally occurring minority variation that is neither more nor less valued than any other variation per se. Cultural variability of meanings attached to forms of impairments which would attract a label of autism in different cultures are diverse (see Grinker, 2007).

Conyers (2003:147-148) identifies some weaknesses of the cultural model that: i) fails to resolve some of the difficulties faced by disabled people, ii) regardless of disability type, has been applied to all disabled people within the same culture, iii) fails to address the multiple challenges of disabled people from varied ethnic and minority backgrounds. Nevertheless, disabled people are still affected by cultural expectations associated with disability. Groce (2000) argued that disability seems to have been differently categorized across cultures and determined by a number of variables concurrently, rather than by single variables such as the presence of impairment. In Euro-American modern thinking, disability is the assumption of the desirability of equality (Whyte & Ingstad, 1995) and there is heavy emphasis on the independence of marginalized people with disabling conditions (Fine & Asch 2000). Groce (2000) has argued that in Western studies seeking to determine the social status of all disabled people, difference in social expectation, for instance between those who are blind and those who are mobility impaired, may be missed. In non-Western cultures, however, disability is seen as a manifestation of misfortune caused by others, oneself or God, as simple fate, or the

unhappy consequence of misdeeds in a previous existence (Wang & Martinson, 1996; Yoshida & Odette, 1999; Miles, 2000; Peters, 2000; O'Hara, 2003; Cho, Y.T., 2004; Choi & Lam, 2001).

Culturally embedded stereotypes of disability affect the ways in which disabled people are seen and see themselves, which in turn affects the ways in which family members, friends, and others interact with disabled people (e.g. Peters, 2000; Rao, 2006). In relation to socio-cultural theory, Vygotsky (1993) presented a dynamic view of disability<sup>7</sup> in which 'primary' disability (e.g. visual and hearing, language and speech-related impairment) lead to exclusion from the socio-cultural environment, which in turn causes 'secondary' disability. 'Primary' disability may lead disabled people to display a distorted connection to their own culture. In all societies, disability is linked to stereotypes that form the basis of misinformation at individual and community levels. In this context, we acknowledge the stigma associated with the label 'disabled'. Goffman's (1963) theory of stigma has had a significant influence on the cultural model that formulates the experience of disability as stigmatizing, liminal, and interstitial (Devlieger, 2005). Burke (2007:16) identified three aspects of stigma associated with disability: i) social (self realization of how others treat disabled people in daily life interactions), ii) situational (how location and place impact on identities of disabled people), and iii) structural (how people in authority treat disabled people). In addition, Barnes & Mercer (2003:8) argue that negative attitudes and behaviour towards disabled people may be extended to other family members as a 'courtesy stigma' (Goffman 1963). Similarly, Burke (2004:26-27) refers to the experiences of siblings of disabled children as 'disability by association' arguing that negative attitudes toward disability could influence siblings' concept of self.

Overall, concepts of disability can be influenced by the prevailing cultural views. The cultural model of disability allows me to clearly see and understand the connection between wider society and the experiences of siblings living with autistic children. Cultural considerations of value systems and welfare policies offer strong potential to gain insights into the subtleties underlying the relationship between culture and

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<sup>7</sup> Vygotsky (1993:67) argued that the psychological makeup of a [disabled] person arises not primarily from the physical impairment itself [primary defect], but secondarily as a result of those social consequences caused by the defect



disability. In this thesis, despite prevalent negative and stigmatizing attitudes to disability in Korea I will focus on realistic representations of siblings' daily lives.

## 1.4. Outline of the Chapters

In Chapter 2, I review theoretical and empirical literature with relevance for my study of the siblings of disabled children. I focus on literature reflecting four different theoretical approaches: i) social psychological, ii) young carers, iii) the new sociology of childhood, and iv) the cultural perspective that is used to illuminate the position of Korean siblings. I evaluate each in turn, identifying their strengths and limitations in aiding understanding of siblings' experiences and end by defining the research questions for this study.

Chapter 3 provides a brief critical review of i) the conceptual understanding of disability in Korean culture, ii) the development of Korean welfare policy and legislation with application for disabled children and the lack of attention to siblings of disabled children in current policy and legislation, iii) current sources of support (financial, educational, and social) for disabled children and their siblings.

In chapter 4, I examine the methodological implications for accessing the world views of siblings of autistic children, that have been neglected in earlier research. I argue that researching children's lives and experiences is likely to be more effective by positioning the children as researchers, competent to guide the 'camera' in recording their thoughts, experiences, understanding and perspectives. I further explore the use of visual ethnography as a method, arguing its appropriateness for accessing the daily life experiences and personal worlds of children living with autistic siblings. These experiences and worlds cannot be accessed via a value free *Archimedean Perspective* (Goldman-Segall, 1998) by an adult, male researcher without experience of living with an autistic sibling. I present the experience of using these tools and techniques in a pilot study conducted in the UK, outlining the lessons learned from my first attempt to engage children as researchers. I also examine the limitations of the popular software for qualitative data (*Nvivo*) and describe the exploration of new software (*Transana*) in

the management and analysis of visual data. I go on to address issues of field research in the main study where I engaged with siblings of autistic children in Korea as researchers. I describe the use of visual methods (video diary and home movie) as the tools and techniques for data collection, and the use of *Transana* and its capacity to link visual, audio and written data that permits simultaneous analysis of different sources of data referring to the same 'event' or 'observation'. Chapter 4 ends with a discussion of the ethical issues raised in gaining access, during the process of data collection, data analysis and presentation of the thesis.

Chapters 5, 6, 7 and 8 present four sets of findings. Chapter 5 is concerned with the meaning of 'being a sibling' of an autistic child that is linked to notions of sacrifice and filial obligation. This chapter illustrates how siblings' sacrifice is shaped according to Confucian familist expectations relating to gender and birth order, and how this extends across the life span.

Chapter 6 examines how the siblings experience and portray their autistic brother or sister, and their relationships using the notion of 'same but different' (Devlieger *et al.*, 2003:10). I unearth the siblings' interpretations of the construction and patterns of interpersonal relationships with their autistic brother or sister. These are shaped by the strong cultural value attached to all sibling relationships and achieved through the development of *Jeong* and *Woori*.

Chapter 7 examines the experiences of siblings that form part of the taken-for-granted aspects of everyday life at home and in the wider society. The focus of this chapter is on the construction of 'ordinariness' in daily life with an autistic child. In particular, I examine how siblings' family lives are influenced by Confucian familist values of 'harmony' as well as the traditional hierarchical structures of the family. And I explicate the means by which siblings reframe autism as part of ordinary daily life in ways that protect them from the stigmatizing reactions to autism that are common in wider society.

In chapter 8 I turn from resilience and the 'ordinary' to focus in more detail on the persistent vulnerabilities expressed by siblings. I argue that the very strengths associated

with strong cultural values attached to sibling relationships paradoxically contribute to their vulnerability.

Chapter 9 presents a discussion of the findings of the previous four chapters drawing out significant insights from the empirical data and relating these to the theoretical perspectives and earlier empirical knowledge presented in chapter 2. I show that despite the pervasive influences of Westernization and globalization on Korean society, the persistent strength of Confucian familist values limits the value of theoretical perspectives taken from the fields of social psychology, new sociology of childhood including children's rights, and young carers. Making sense of the daily life experiences and expectations of the siblings of autistic children demands the theoretical insights offered by socio-cultural perspectives.

The final chapter offers: i) an overview of the implications of my findings for each of the research questions, ii) a description of the contribution of this study to knowledge about siblings of disabled or chronically ill children, iii) implications for the development of Korean welfare policy, iv) reflections on the research process and v) suggestions for further research.

## **Chapter Two**

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# **Understanding the Experiences of Siblings of Disabled Children**

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## 2.1. Introduction

Children who grow up together in the same family form unique bonds (Cicirelli, 1995). The bond with siblings is the longest we will ever have, and that experience impacts on development throughout the life cycle (Cicirelli, 1995; Dunn, 2000; 2004; 2005). But when a child is diagnosed with a disability or chronic illness, all family members are confronted with severe distress (McHale & Harris, 1992; Giallo & Gavidia-Payne, 2006; Houtzager *et al*, 2005). In this context, the presence of a disabled child creates unique experiences within families. In this chapter, key literature on the impact of childhood disability on siblings will be reviewed, to provide the background for this study. In particular, I examine four main bodies of literature that have presented different ways of understanding the complex experiences and lives of siblings of disabled children.

The second part of the chapter examines siblings of disabled children through *social psychological perspectives*. A wealth of literature has been devoted to these perspectives. Here, I focus on: i) the positive and negative impacts of the presence of a disabled (especially autistic) child on their siblings, ii) variables (siblings, parent, family and contextual) reflected in the complex outcomes of the presence of a disabled child. The third part of the chapter explores the literature relating to siblings as *young carers*, a perspective that focuses on the caregiving implications for siblings of a disabled brother or sister. In the fourth part of the chapter, I examine the *new sociology of childhood* in which siblings are considered as social actors who provide their own perspectives on the experiences and consequences of being siblings of a disabled child. In the fifth part of the chapter, I explore the literature that addresses *cultural aspects of siblinghood* globally, and in Korea. The chapter concludes by arguing that contemporary literature contains substantial evidence and argument focusing on: i) the psychosocial impacts of being the sibling of a disabled child (see e.g. Kaminsky & Dewey, 2001), ii) siblings as ‘young carers’ (see e.g. Burke, 2004), and iii) parents’ views of siblings’ experiences (see e.g. Mulroy *et al.*, 2008). But there are significant gaps in knowledge and understanding of the lives of siblings of disabled children as depicted by the children themselves, and a wealth of information to be gleaned by listening to their accounts and observing their images of ordinary, everyday life within

their sociocultural contexts (see e.g. Cicirelli, 1995), a further aspect that has been neglected in contemporary literature.

## **2.2. Children Affected by Sibling Disability: Social Psychological Perspectives**

This part of the chapter examines siblings of disabled children through social psychological perspectives. Most psychological studies concerning siblings' experiences of disability and chronic illness identify disabled children as potential stressors in the lives of their siblings (e.g. Daniels *et al.*, 1987; Gamble & McHale, 1989; Lobato *et al.*, 1988; Gardner, 1998; Cox *et al.*, 2003; Shudy *et al.*, 2006). Sections 2.2.1 and 2.2.2 examine, respectively: i) the impact of having a disabled brother or sister on their sibling; and ii) the (particular) variables that affect siblings and the ways in which they affect them.

### ***2.2.1. The Impact of Disabled Children on Their Siblings***

Siblings generally spend more time with their disabled brother or sister than their parents, not only during childhood, but also throughout the course of their lives. A wealth of literature has been devoted to psychological coping mechanisms or the adjustment of siblings, but it has yielded inconsistent outcomes that can be categorized into emotional, and behavioural effects (e.g. Lobato, 1990; McHale & Gamble, 1989; Dyson, 1999; Seltzer *et al.*, 2005).

#### ***2.2.1.1. Emotional Effects***

The literature on emotional effects suggests that the internalized effects of having disabled siblings can exacerbate the risks of emotional stress, manifested through depression, loneliness, anger, confusion, guilt, sadness, anxiety, resentment, embarrassment, and jealousy (Howlin, 1988; McHale & Gamble, 1989; Meyer &

Vadasy, 1994; Cuskelly, 1999; Nixon & Cummings, 1999; Lobato & Kao, 2002; Sloper, 2000; Opperman & Alant, 2003; Sharpe & Rossiter, 2002).

In research conducted in the United States, with 59 siblings of autistic children and 67 siblings of normally developing children, DeMyer (1979) found that 30% of siblings of autistic children showed feelings of neglect, and 18% of parents reported that at least one sibling seemed worried and anxious. Bågenholm & Gillberg's (1991) study of 20 Swedish siblings of autistic children showed that 35% had high levels of loneliness and problems with social networks, while the comparison groups of siblings of normally developing children and of 'mentally retarded'<sup>8</sup> children did not report problems of loneliness. A study conducted in Canada by Gold (1993) also confirmed higher levels of self-reported depression among brothers of autistic children compared to those of normally developing boys. Roeyers & Mycke's (1995) study, conducted in Belgium, reported that siblings of autistic children experienced more stressors including embarrassment in the presence of their peers and difficulty in dealing with peer reactions to their autistic brother or sister. These findings were consistent with Ross & Cuskelly's (2006) Australian study that found 40% of siblings of autistic children reported by their mothers to have significant coping problems, predominantly internalizing difficulties. And Lainhart's (1999) review of literature related to psychiatric problems in individuals with autism, their parent and siblings, argued that the burden of raising an autistic child may also contribute to the development of psychiatric problems in their siblings.

On the other hand, not all siblings of disabled children have been reported to have elevated levels of emotional difficulties. The literature contains evidence of positive effects of having a disabled brother or sister, including increased empathy, pity, patience, honesty, maturity, affection. (e.g. McHale & Gamble, 1989; Tozer, 1996; Eisenberg *et al.*, 1998; Stoneman, 2001; Cuskelly & Gunn, 2003; Dykens, 2005; Benderix & Sivberg, 2007), although there is a degree of variation in these positive emotional effects. For instance, while Pit-ten Cate & Loots (2000), working in Holland, report both love and

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<sup>8</sup> The term 'mentally retarded' or 'mental retardation' is used in this thesis **only** where I am referring directly to published work that uses this term. I use the terms 'autistic' to refer to the eight brothers and one sister of the child participants (siblings) in this study who have been diagnosed as being autistic. I use the terms 'autistic' and 'disabled' when referring to the work of other researchers, reflecting the terms they have used in their published studies.

affection toward physically disabled siblings and enjoyment in playing together, they also report difficulties in playing physical games and in communicating with each other, due to the disability. Levy-Wasser & Katz (2004) have found that 'mental retardation' in the family does not necessarily lead to neglect of siblings, and may even be a catalyst for emotional growth.

These findings chime with studies of siblings of autistic children that indicate positive adjustment and positive relationships (Bägenholm & Gillberg, 1991; Mates, 1990; Gold, 1993; Rodrigue *et al.*, 1993; Kaminsky & Dewey, 2002; Pilowsky *et al.*, 2004). Miller (2001:22) found that the overall responses of siblings towards their autistic brother or sister were very positive, with no apparent feelings of jealousy or rivalry. Miller's research showed that siblings do experience some negative feelings about their autistic brother or sister but, nevertheless, loved them. These findings are consistent with a Canadian study by Kaminsky & Dewey (2002), who worked with siblings (aged 8-18) of: i) 30 autistic children, ii) 30 children with Down's syndrome, iii) 30 normally developing children. Analysis of questionnaires completed by the siblings found no significant differences in loneliness between siblings of autistic children, and the two comparison groups.

In summary, evidence from the literature presents a mixed picture, reporting negative, neutral, and positive emotional effects on siblings of the presence of disabled, including autistic, children.

### **2.2.1.2. Behavioural Effects**

Having a disabled brother or sister is frequently reported as resulting in behavioural difficulties such as aggression, self-injury, impulsivity, hyperactivity, temper tantrums and obsessional, ritualistic behaviours, which may preclude an ordinary everyday life (e.g. Gray & Holden, 1992; Harris, 1994; Nixon & Cummings, 1999; Hogan *et al.*, 2003). Fussell *et al.* (2005) report parallel findings for siblings of children with ADHD<sup>9</sup> in the United States, as do Cuskelly & Dadds (1992) for siblings of children with

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<sup>9</sup> Attention-deficit hyperactivity disorder



Down's syndrome in Australia, Stawski *et al.* (1997) for siblings of chronically ill children in Israel, and Rossiter & Sharpe's (2001) review of studies of siblings of 'mentally retarded' children.

Similar findings for siblings of autistic children are reported by Bågenholm & Gillberg (1991), who attempted to identify whether siblings of autistic children exhibit more behavioural problems (e.g. attention and conduct problems) than those of 'mentally retarded' children. They report that siblings of autistic children are more negative in describing their sibling relationships than the comparison groups. This negativity was linked to disturbance of privacy and breaking of their belongings by their autistic siblings. These results have been confirmed by later research. For instance, Rodrigue *et al.* (1993) found that siblings of autistic children have more internalizing (e.g. depression, anxiety) and externalizing (e.g. aggression, defiance, or running away) behavioural problems than comparison groups, especially siblings of normally developing children. In a three year longitudinal Canadian study, Fisman *et al.* (1996) reported a greater risk of externalizing and internalizing behaviours in siblings of children with pervasive developmental disorder compared to those of children with Down's syndrome and normally developing children. They show that warm and non-conflictual sibling relationships developed by siblings of normally developing and Down's syndrome children act as protective factors. But siblings of children with pervasive developmental disorder do not readily form such warm and non-conflictual relationships. Similar findings emerge in other recent studies, which indicate that sibling relationships in families of autistic children are characterized by less intimacy, less prosocial behaviour and less nurturance (Kaminsky & Dewey, 2001). Kaminsky & Dewey (2002) also report siblings, especially brothers, of autistic children as having the lowest levels of social competence.

Verté *et al.* (2003) found that the siblings of high functioning autistic children reported more behavioural problems than those of normally developing children. In particular, those aged between nine and eleven years were reported as having significantly more behaviour problems. These findings are consistent with Ross & Cuskelly's (2006) work in which 40% of siblings of autistic children were reported by their mother to have

significant adjustment problems, predominantly difficulties such as aggression and anger.

In contrast, other studies report that having a disabled sibling can be beneficial, leading to greater maturity, responsibility, altruism, tolerance, self confidence, independence and less conflict in their relationships when one sibling is disabled or chronically ill (McHale & Gamble, 1989; Fisman *et al.*, 1996; Pit-ten Cate & Loots, 2000; Mandleco *et al.*, 2003; Connors & Stalker, 2003). Growing up with a disabled or chronically ill child may offer a greater level of understanding and emotional development to siblings who may develop greater leadership skills, especially in areas where understanding and sensitivity to human awareness issues are important. Indeed, Dunn (2000) has argued that all sibling relationships offer children opportunities to learn about and better understand other people as well as themselves.

Numerous studies have failed to find serious problems in relation to internalizing or externalizing behaviours (Stoneman, 2001; 2005). Cuskelly *et al's* (1998) work, conducted in Australia, found no significant conduct problems among siblings of Down's syndrome children. Nor did they find any difference in the level of problem behaviours compared to siblings of normally developing children. Research conducted by Lardieri *et al.* (2000) in the United States, whose findings were derived from a *Sibling Relationship Questionnaire* and a *Sibling Impact Questionnaire*, found that: i) siblings of children with learning difficulties held strong feelings of love and affection for one another, and ii) the siblings' maturity was signalled by their tolerance for individuals with differences, and their patience in dealing with others. Within the family environment, Cox *et al's*, (2003) work with 46 siblings of disabled children in the United States collected verbal responses to a sentence-completion activity regarding coping responses to stressful situations in everyday life. They reported that most siblings' responses were proactive, with siblings taking personal responsibility for changing or improving stressful situations in either a cognitive or physical manner. As with the studies cited earlier in this section, studies conducted in the 1990s and more recently suggest there is no difference in self-concept or in perceived competence between groups of children who have and do not have a disabled sibling (Stoneman, 2005).

These findings are consistent with other studies (e.g. Mates, 1990; Gold, 1993; Miller 2001; Kaminsky & Dewey, 2002; Pilowsky *et al.*, 2004; Macks & Reeve, 2007), that have focused specifically on the siblings of autistic children. The American study conducted by Mates (1990) found that siblings of autistic children had a high level of positive self-concept, healthy academic performance and behavioural adjustment as assessed by parents and teachers. This is similar to the findings of Pilowsky *et al* (2004), whose study of socialization skills and behaviour problems, conducted in Israel, showed that 86.7% of the siblings of autistic children were found to be functioning well judged against established base-lines. In a study conducted by researchers in Belgium (Verté *et al.*, 2003), 12 to 16 year old sisters of children with high functioning autism were reported to have higher feelings of social competence and a more positive self-concept than sisters of normally developing children, although other studies have found no differences (e.g. Rodrigue *et al.*, 1993; Dyson, 1996; Hannah & Midlarsky, 1999; Fisman, *et al.*, 2000). Yirimiya *et al's* review of the literature (2001) concludes that the overall effects of having an autistic brother or sister on children's behavioural and emotional problems are non-significant.

To summarise, while the presence of disabled children appears to have a significant influence on their siblings' lives, there is little consistency in the findings of research investigating the emotional and behavioural effects on siblings of living with autistic or other disabled children. The findings can be broadly categorized into 'positive effects' 'negative effects' and 'no/inconsistent effects' (see Table 2-1). There is some evidence to suggest that the impact of living with a disabled child alters with the developmental stage of the sibling (Powell & Gallagher, 2005; Moore *et al.*, 2002; Seltzer *et al.*, 2005). But, even allowing for variations based on developmental stage, I argue that the existing literature tends to adopt a narrow perspective in seeking evidence of threats to the well-being and quality of life of siblings, focusing particularly on emotions and behaviours, rather than taking a more holistic view of the lives of siblings.

**Table 2-1** Evidence of the Emotional and Behavioural Effects on Siblings of Living with Autistic or Other Disabled Children

Positive effects	Negative effects	No/inconsistent effects
Admiration	Aggression	Child's appraisal of sibling relationship
Affection	Agonistic(aggressive) behaviour	Frequency and quality of sibling interaction
Companionship	Antagonism	Imitation
Conflict resolution skills	Arguing/fighting	Involvement
Cooperation	Avoidance	Length of fantasy play
Cooperative pretend play	Coercive power/control	
Empathy	Competitive behaviour	
Harmony	Conflict	
Positive activities	Hostility	
Positive affective climate	Negative activities	
Positive behaviour	Negative affective climate	
Positive power/control	Negative behaviour	
Positive relationship qualities	Negative relationship qualities	
Positive sibling interaction	Negativism	
Positivity	Negativity	
Prosocial behaviour	Rivalry	
Prosocial sibling interaction	Sibling conflict	
Warmth		

(Cited from Sanders (2004) *Sibling relationships: theory and issue for practice* p.75)

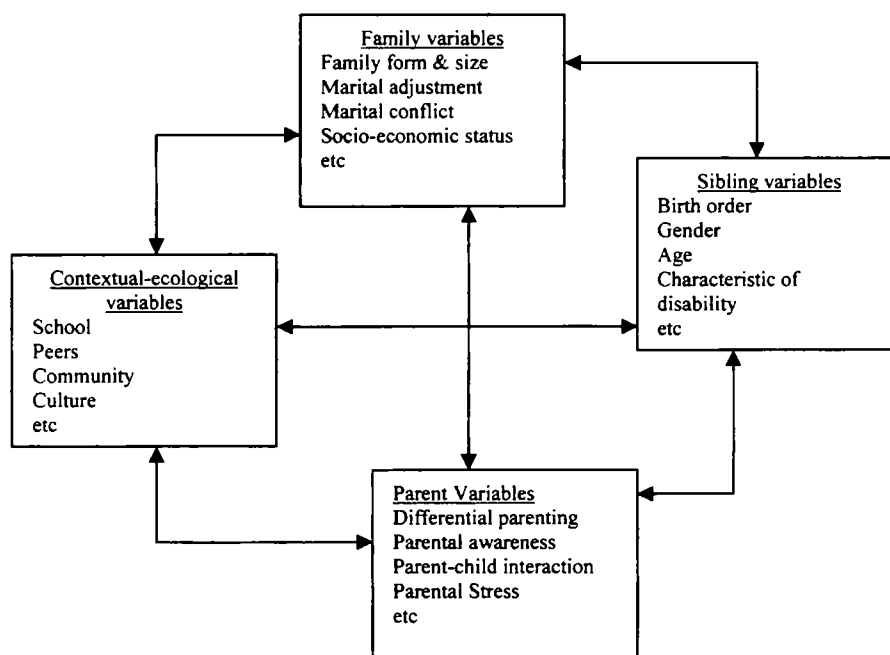
### 2.2.2. Variables that Influence the Impact of Disabled Children on Their Siblings

The experience of being a sibling of an autistic child does not occur in isolation. General studies linking children's vulnerability and familial circumstances such as poverty and social exclusion indicate complex relationships between vulnerability, risk and resilience (e.g. Garmezy, 1993). But the extent to which family circumstances affect vulnerability in the siblings of autistic children is not known. Orsmond & Seltzer's (2007a:317) review of the literature on the well-being of such siblings concludes that:

“the literature yields mixed results regarding whether there is a negative impact on siblings when they have a brother or sister with ASD [autistic spectrum disorders], perhaps due to genetic (i.e. broader autism phenotype) and environmental influences. ....The variability in these findings is possibly due to small sample sizes, differences in age ranges of siblings who participated, and different measures used to examine well-being and adjustment.”

Many different complex, interconnected, inter- or intra-familial factors are involved in the successful development of siblings (Dunn, 2005). Many psychological studies related to siblings of disabled children have identified mediating factors including fixed characteristics (e.g. age, gender, birth order, severity of disability conditions), and moderating variables such as family roles and relationships (see for review Powell & Gallagher, 2005; Moore *et al.*, 2002; Stoneman, 2005). These factors, illustrated in Figure 2-1, are distilled into four different areas: sibling variables, parent variables, family variables and contextual-ecological variables. However, there is little consistency in the literature about the nature and strength of their influence on outcomes for siblings.

**Figure 2-1** Illustration of Influencing Variables



### 2.2.2.1 Sibling Variables

Sibling variables have been found to have significant influence on the relationship between disabled children and their siblings. Much research has concentrated on sibling characteristics such as birth order, age, age-spacing, gender and characteristics of the disability (see Moore *et al.*, 2002; Powell & Gallagher, 2005). There are conflicting findings regarding birth order and gender. Sisters or siblings born after disabled children

are reported to be adversely affected. For example, Williams' (1997) review of the literature argues that older sisters and younger brothers of chronically ill children show higher levels of behaviour problems. In particular, younger brothers tend to have problems related to aggression and delinquency, whereas older sisters have difficulties with depression and anxiety. Silver & Frohlinger-Graham's (2000) study, conducted in America, reported that the potential risk factors and causal processes that influence distress operate differently depending on sibling birth order, gender, or their combination, which is similar to the findings of a Korean study (Lee, E.J., 2001). Other research has identified difficulties experienced by younger children, especially boys (Hastings, 2003a), whose disabled siblings are older (Cuskelly, 1999; Guite *et al.*, 2004). However, McHale *et al.* (1986), reporting findings from the USA, argue that age and gender variables in siblings do not appear to make much difference to the quality of the relationship between disabled children and their siblings. In the UK, Hastings (2003a) also reports uncertain effects of age and gender on sibling adjustment. Harris (1994:14) importantly argues that the relationship between age and gender is complex and not consistent. Kim, H.R., (2006) also argues that different combinations of gender, birth order and same school participation are not associated with levels of stress in siblings of 'mentally retarded' Korean children. The gender of siblings is more closely associated with caregiving responsibilities, sisters being more likely than brothers to provide care for their disabled siblings (Orsmond & Seltzer, 2000; Davis & Salkin, 2005; McGraw & Walker, 2007). Gold (1993) argues that brothers of autistic children actually do less domestic work than siblings of normally developing children. I return to this issue in section 2.3.

Conflicting evidence is also found regarding the age difference between disabled children and their siblings. Lobato (1990) and Stoneman & Brody (1993) argue that closer age-spacing between siblings is associated with negative interaction patterns, while wider age-spacing is correlated with positive sibling adjustment (Powell & Gallagher, 2005). Shin, H.J., (2000), however, reported that Korean children with older autistic siblings are more negatively affected when the age gap is of 3 years or more. Breslau's (1982) American study showed that younger boys, specifically those close in age to the disabled sibling, scored higher on psychological impairment than older boys. Among girls, however, age-spacing was not significantly related to psychological

functioning. Importantly, a number of literature reviews show that this dynamic variation in relationships between variables continues beyond childhood into adulthood (e.g. Harris, 1994; Nixon & Cummings, 1999; Dyson, 1999; Moore *et al.*, 2002; Ratcliffe, 2003; Orsmond & Seltzer, 2000, 2007a, b).

Further variables associated with the likelihood of problems for siblings are the nature and severity of the disabilities (Seligman & Darling, 1997; Fisman *et al.*, 2000; Jeon, J.H., 2002; Moore *et al.*, 2002; Powell & Gallagher, 2005). For example, Gold (1993) and Stoneman (2001) argue that the greater severity of the disability, the more adverse the effect on the sibling. A Greek study conducted by Dallas *et al.*, (1993) reported that the interaction between siblings tended to become less egalitarian as disability increased, and cooperative behaviours declined. However, other researchers (e.g. Sharpe & Rossiter, 2002) demonstrated little difference related to the severity of the disability. Opperman & Alant (2003:441) reported that behavioural problems of disabled children in South Africa seem more indicative of distress levels in all family members, than the severity of the disability itself.

The specific condition of disabled siblings is identified as a significant factor in a range of studies (see review by Cuskelly, 1999). In relation to autism, Kaminsky & Dewey (2001) reported that sibling relationships with autistic brothers or sisters are characterised by less pro-social behaviour (linked to communication and interaction difficulties in the autistic child) than sibling relationships involving children with Down's syndrome, or normally developing children. In the UK, Knott *et al.* (1995) reported that autistic children tend to initiate i) less pro-social (cooperating, sharing, physical affection etc) and ii) agonistic interactions (physical aggression, object struggle, threat etc) with their siblings than Down's syndrome dyads. Moreover, Miller (2001) reported that the experiences of the siblings of autistic children are more demanding, and characterised by adversity, than those of siblings of normally developing children. Such experiences can lead to negative attitudes about their sibling relationships and interactions. In contrast, Miller's (2001) study of three different sibling groups (autism, learning disabilities, normally developing) showed that siblings displayed positive behaviours toward their disabled siblings, with no apparent feelings of jealousy or rivalry. And in a study of thirty siblings of autistic children measuring socialization skills and behaviour problems, Pilowsky *et al.* (2004) found that 86.7% of the siblings

were functioning well and did not differ from two comparison groups (siblings of children with mental retardation of unknown genetic aetiology, and children with developmental language disorders) on any of the measures. Moreover, Roeyers & Mycke (1995) reported that siblings of autistic children have a fair understanding of autism. There is also an association between children's knowledge of autism and the quality of the sibling relationship (e.g. Harris, 1994; Glasberg, 2000). This mixed picture of the effects of specific conditions is summed up by Cuskelly (1999) who concludes that "all of the studies which examine the issue of differential effects for siblings have reported that different illnesses have different sequelae for the siblings" (p.114)

To summarise, these mixed findings suggest that characteristics of both disabled children and their siblings contribute to the lived experiences of siblings, although the patterns of interaction between wide ranging variables that have been hypothesised as likely to have an impact on siblings appear to be highly nuanced in ways that have so far evaded the establishment of consistent patterns.

#### ***2.2.2.2. Parent Variables***

Parental characteristics and behaviours are important in determining outcomes for the siblings of disabled children. Disabled children require a great deal of parental time, attention and resources, and their siblings may not receive the same attention (Howlin, 1988). The experiences of siblings of disabled children are heavily affected by parental behaviour (e.g. Honey & Halse, 2006). For instance, parental behaviours linked to psychological status, such as anger and complaints (McHale & Gamble, 1989) or depression (Cuskelly & Dadds, 1992), parental stress (Cuskelly *et al.*, 1998; Baxter *et al.*, 2000; Fisman *et al.*, 1996, 2000; Dyson, 2003), parent mood (Williams *et al.*, 1999) and parental attitudes (Gold, 1993; Gupta & Singhal, 2005) are important factors that appear to be related to negative outcomes (e.g. negative self-concepts, social skills, behaviour problems, or low social competence) in siblings of disabled children.

Conversely, Hastings (2003a) argues that parental stress is not a strong factor in determining the behaviour of siblings. More generally, children's perceptions of



parental sensitivity are related to the extent to which parents are aware of their attitudes and perceptions towards their disabled siblings (Taylor *et al.*, 2001; Grissom & Borkowski, 2002). Related to this, the amount of parent-child communication around problematic issues and knowledge of disability is also crucial in determining outcomes for siblings (Sidhu *et al.*, 2005; Eom, J.W., 2004). For instance, Van Riper's (2000) study, conducted in the USA, showed that problem-solving communications within families have been related to greater social competence in siblings of Down's syndrome children.

The quality of interpersonal relationships between parents and non-disabled children is argued to have a crucial influence on relationships between disabled children and their siblings (e.g. Levy-Wasser & Katz, 2004; Maleki-Tehrani, 2006). In siblings of normally developing children, Dunn (2000:245) comments that differences in parent-child relationships among siblings are likely to result in more conflictual and hostile sibling relationships, and difficult behaviours and conduct disorders among '*unfavoured siblings*', especially when they are under stress (see also Stocker & McHale, 1992; Brody & Stoneman, 1996; Jodl *et al.*, 1999; Dunn & Kendrick, 1982; Brody, 1998; Dunn *et al.*, 1999). A similar pattern might be expected in siblings of disabled children. Parenting strategies such as differential treatments of non-disabled children are associated with increased difficulties in siblings who experience perceived parental favouritism of their disabled brother or sister (McHale *et al.*, 1986; Foster *et al.*, 2001; Wolf *et al.*, 1998; Kim, H.K., 1998).

However, these findings are challenged by other studies. For instance, Stoneman (1998; 2001) found that differential treatment may not necessarily be interpreted as parental favouritism, but as a justified parental response to the greater needs of disabled children. Lähteenmäki *et al.*'s (2004) Finnish study of siblings of children with cancer found that problems associated with differential attention between the child with cancer and the sibling(s) following diagnosis, diminished after the sick child's first treatment when the parents regained at least some energy enabling them to pay attention to the sick child's siblings. This attention led to better adaptation by the siblings to the child's illness. A similar finding is reported in Miller's (2001), research on the impact of parental behaviour on the relationships between autistic children and their siblings. He found

that parents giving less attention to siblings did not increase feelings of jealousy or rivalry.

Overall, the literature on parental variables mirrors the inconsistencies in the literature on sibling variables. There is evidence of factors that can place siblings at greater risk of, and factors that can protect them from, negative outcomes related to mental health and quality of sibling relationships.

### ***2.2.2.3. Family Variables***

Well-functioning and healthy families can help siblings of disabled children to succeed (Stoneman, 2005:343). Therefore, multiple, interactive, family variables can also be expected to have powerful influences on the adjustment and well-being of siblings of disabled children, based on a family system perspective (e.g. Seligman & Darling, 1997). This theoretical perspective emphasises the interconnectedness of each family member (Sanders, 2004) and the complex system of relationships is crucial for understanding a range of relevant individual and family outcomes. Family variables are closely associated with the sibling relationships (Stoneman, 2005); marital satisfaction (Rodrigue *et al.*, 1993), marital stress (Lardieri *et al.*, 2000; Rivers & Stoneman, 2003), family conflict (Lynch *et al.*, 1993; Nixon & Cummings, 1999), family cohesion (McCusker *et al.*, 2002), family environment stimulus (Jin, M.S., 2001), socio-economic status (Opperman & Alant, 2003), maternal dissatisfaction with external social support and disruption to day-to-day family life as a consequence of 'physical disorder' (Sloper & While, 1996).

Research on the impact of family variables on sibling relationships has demonstrated mixed outcomes for siblings of disabled children. Rivers & Stoneman's (2003) American study, based on the importance of considering family context as a contributor to the quality of sibling relationships, showed that siblings of autistic children in families experiencing high levels of marital stress, and who seek greater support from formal sources outside the family, report a higher level of negative sibling behaviours than those in similar families who seek low levels of formal support. In an Australian study conducted by Giallo & Gavidia-Payne (2006), parent and family factors (e.g.

socio-economic status, past attendance at a sibling support group, parent stress, family time and routines, family problem-solving and communication, and family hardiness predicted sibling adjustment difficulties) were found to be stronger predictors of sibling adjustment difficulties, than the siblings' own ratings of stress and coping. Van Riper (2000), who examined relationships between family demands, family resources, family problem-solving communication, family coping, and sibling well-being in 41 families of children with Down's syndrome, found that the well-being of siblings was generally higher in families with lower levels of family demands, greater family resources, higher levels of family coping, and higher levels of affirming, problem-solving, communication. Similarly, strong marital relationships, family cohesion, and low level of family conflict have been related to positive sibling relationships, high self-competence, and low level of psychological and behaviour problems in siblings of disabled children (e.g. Rodrigue *et al.*, 1993; Mandleco *et al.*, 2003; Rivers & Stoneman, 2003).

In contrast, several other studies suggest that family variables do not have very strong effects on sibling adjustment to disability (McHale *et al.*, 1986; Mates, 1990; Gold, 1993; Hannah & Midlarsky, 1999; Roeyers & Mycke, 1995; Eisenberg *et al.*, 1998). A Canadian study conducted by Dyson (1996) reports that families of learning disabled children are similar to other families in terms of having a positive and cohesive family relationship. Mandleco *et al.*'s (2003) study, conducted in the USA, also found that family conflict, marital conflict, and external locus of control orientation are similar between families with or without disabled children.

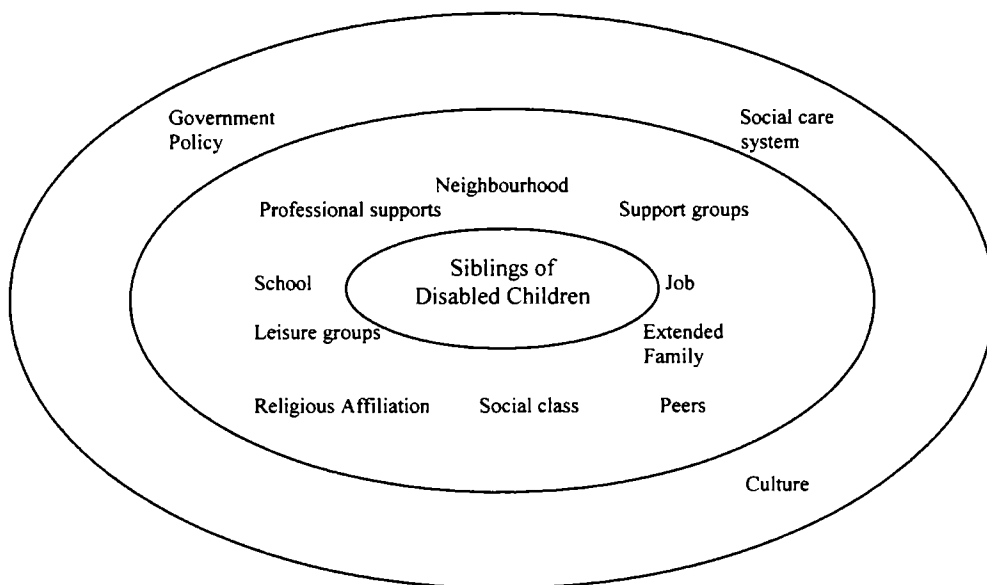
Overall, the evidence suggests that the influence of family variables on the experiences of siblings of disabled children is a very complex matter. Although it is commonly acknowledged that a child's disability has an impact on all family members, the term 'impact' has mixed meanings and mixed connotations.

#### **2.2.2.4. Contextual Variables**

In addition to sibling, parental and family variables, the experiences of being a sibling of a disabled child may be influenced by broader contextual factors (McCubbin *et al.*,

1993; Kim, Y.S., 2001), based on ecological theory (Bronfenbrenner, 1979, see review Volling, 2005). The literature suggests that the experiences of siblings of disabled children are dependent on various contextual influences (see Figure 2-2) (Lobato *et al.*, 1988; Stoneman, 2005; Hodapp *et al.*, 2005), although there is little consistency in measures of, for example, sibling relationship, sibling interaction, adjustment.

**Figure 2-2** Contextual Variables Influencing Siblings of Disabled Children

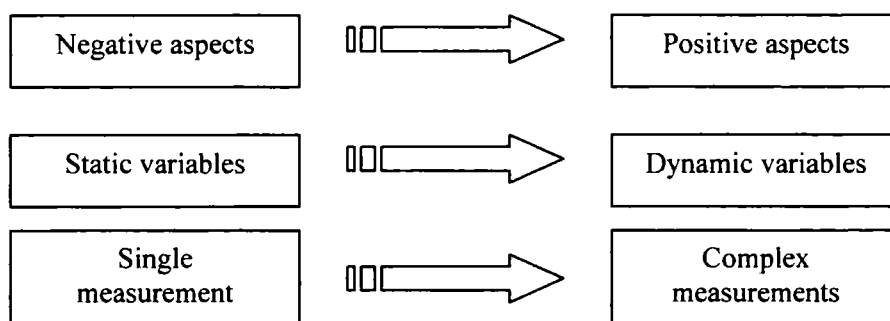


For instance, poor economic circumstances (Olssen & Hwang, 2003), low social class (Sloper & While, 1996), poor peer relationships (Bägenholm & Gillberg, 1991; Connors & Stalker, 2003), difficult relationships with extended family (Kendall, 1999), difficulties in school (Hannah & Midlarsky, 1999; Seo, M.S., 2004), and restricted social activities (Howlin, 1988) have been related to negative experiences of siblings. In particular, negative societal attitudes towards disabled children present specific challenges to their siblings who are faced not only with the social exclusion of their disabled sibling, but with their own experience of social exclusion (Seligman & Darling, 1997). This finding is echoed by Connors & Stalker's (2003) study in the UK, that found children experiencing a sense of injustice resulting from the name calling and staring their disabled brother or sister attracts.

On the other hand, Pit-ten Cate & Loots' (2000) and Baumann *et al.*'s (2005) studies, conducted in the America, showed that having a disabled sibling does not cause problems in relationships with friends. And Eisenberg *et al.* (1998) found that the disabled child's place of residence (in the family home or residential care) had no significant impact on outcomes of psychological adjustment, self-esteem and family environment for their siblings. McHale & Gamble (1987) identified a mediating effect of religion with a positive relationship between psychological outcomes for siblings and higher levels of religious activity in mothers. And welfare supports for disabled children and families, even in different cultural, educational and social policy contexts, have been shown to be important factors in buffering the effects on siblings in potentially stressful situations (Cunningham, 1996; Connors & Stalker, 2003; Burke & Montgomery, 2003; D'Arcy *et al.*, 2005; Lobato & Kao, 2002). These findings suggest that although siblings' adjustment and coping capacities may be influenced by contextual variables, the precise nature of their effects cannot be generalised to all siblings of disabled children.

Overall, social psychological perspectives on the experiences of the siblings of disabled children offer insights into a world of complex and contradictory findings that are not easy to interpret: i) from a theoretical viewpoint (see Figure 2-3), psychological studies of siblings of disabled children have changed over time to focus less on negative aspects and more on positive aspects of the sibling experience. We have been able to learn that although some siblings of disabled children may be at increased risk of developing behavioural and emotional problems, others appear little affected and others still may experience positive effects; ii) psychological studies have also developed over time from the use of static variables (e.g. gender, birth order) to dynamic variables (relations between siblings, family and contextual variables) in order to explore the wide variation of experiences of siblings within and across families; iii) the changes reflected in i) and ii) have been accompanied by the development of more sophisticated instruments for the measurement of psychological outcomes.

**Figure 2-3** The Development of Social Psychological Studies  
focusing on Siblings of Disabled Children



### 2.3. Children Affected by Sibling Disability: the Young Carers' Perspective

Being a sibling involves particular relationships and roles (Dunn, 2000). Siblings often have specific responsibilities for their disabled brother or sister, and they may become the 'keeper' instead of 'kept' (Siegel, 1996:150). Siblings' responsibility for their disabled brother or sister was highlighted as a common theme in section 2.2.2.1. Various studies have demonstrated the expectations placed on children to be involved in the care of their disabled brother or sister (McHale & Gamble, 1989; Horwitz *et al.*, 1992; Horwitz, 1993; Harris, 1994; Tozer, 1996; Pruncho *et al.*, 1996; Seligman & Darling, 1997; Damiani, 1999; Kendall, 1999; Burke & Montgomery, 2000; 2003; Smith *et al.*, 2000; Jewell & Stein, 2002; Hannah & Midlarsky, 2005). An early study conducted by McHale & Gamble (1989), examined 62 children between the ages of 8 and 14. Half had 'mentally retarded' siblings and half had normally developing siblings. Those with 'mentally retarded' siblings reported more time spent in caregiving activities but less time in non caregiving contact with their 'mentally retarded' brothers and sisters than siblings of normally developing children. Bågenholm & Gillberg (1991) also found that siblings of autistic children and those of 'mentally retarded' children viewed themselves as having to work more often around the home than did those of normally developing children. Siegel (1996) argued that a caring role by siblings of

autistic children can lead to loss of childhood when parents, adult caregivers and teachers all accept the adoption of the primary caregiver's role by the sibling. Greenberg *et al.* (1999), conducted a postal questionnaire with 61 American siblings of adults with serious mental illness and 119 siblings of 'mentally retarded' adults. This showed that almost 60 percent of the siblings of 'mentally retarded' adults expected to assume a primary caregiving role in the future, but only one-third of the siblings of mentally ill adults held this expectation. But Harland & Cuskelly (2000), working with six Australian adult siblings of sensory impaired adults between 24 and 34 years old and living at home with at least one parent, found that although mothers were the primary carers and siblings played a secondary role in supporting their disabled brother or sister, siblings provided practical support (e.g. mobility, recreation), communication support, support for the personal development of their disabled siblings (e.g. teaching new skill), and emotional support. Many studies have found that the siblings of disabled children have unexpected housework and expanded caregiving demands compared to their peers without disabled siblings (e.g. Damiani, 1999; Fisman *et al.*, 2000; Cuskelly & Gunn, 2003; Hannah & Midlarsky, 2005).

Other research studies, however, have obtained different results. In interviews with American mothers of children with Down's syndrome, Cuskelly & Gunn (1993) found no difference in reports of responsibility levels for siblings between the ages of six and thirteen and a comparison group of children with normally developing siblings. Similarly, among children with autistic siblings, Gold (1993) found no significant differences in child care and household responsibilities compared to those of normally developing children.

Literature on care taking by siblings of disabled children shows mixed results (see Damiani, 1999). And it cannot be firmly established that siblings of disabled children have more caring and domestic responsibility than those of non-disabled children. But heavy caring responsibilities on the part of siblings have been shown to lead to greater stress levels compared with those of the siblings of normally developing children (for review Lamorey, 1999). Having a disabled brother or sister may lead to a restructuring of non-disabled siblings' roles within the family. Increased caregiving work and restructured roles of siblings of disabled children have been associated with increased

problems such as anxiety, conflict, decreased non-caregiving interaction with disabled siblings, and restrictions on social activities (Stoneman *et al.*, 1988; McHale & Harris, 1992; Cuskelly *et al.*, 1998; Lamorey, 1999). Siblings of disabled children are also disadvantaged in having limited time for themselves and limited opportunities to participate in social activities outside the family (Kaminsky & Dewey, 2002).

But, Newman (2003) argues that the caregiver perspective focuses heavily on negative outcomes for siblings:

The tendency of sibling studies to focus on vulnerability rather than resilience and to be concerned with unsuccessful rather than successful adaptation..... begin from the premise that well children need protection from their disabled siblings, and thus focus on helping the former rather than latter. Conversely, a small number of studies have begun from premise that well children are potential source of valuable help for their ill or disabled sibling. (p.73)

Several studies have claimed positive effects of caregiving such as an increased sense of responsibility, tolerance, altruism, independence and maturity (Lobato, 1990; Tozer, 1996). Cuskelly & Gunn's (2003) Australian study of siblings of children with Down's syndrome found increased caregiving associated with increased empathy. Siegel & Silverstein (1994) argued that non-disabled children tend to take on parental roles and anticipate continuing involvement in their disabled sibling's future care. In becoming caregivers as well as being 'son' or 'daughter', they form an alliance with their parents.

While studies of siblings who have caring responsibilities for their disabled brother or sister have reached inconsistent conclusions, it does seem clear that sibling roles and responsibilities are shaped as caregiver, manager, teacher, or helper (Harris, 1994; Greenberg *et al.*, 1999; Rodger & Tooth, 2004; Powell & Gallagar, 2005; Earl, 2005). In relation to theories of 'parentification'<sup>10</sup>, the specific responsibilities and roles of

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<sup>10</sup> The term '*parental child*' was coined by Minuchin *et al.* (1967, cited in Earley & Cushway, 2002:164-165) to refer to those children who assume a parental responsibility usually as a result of the family's economic or social condition. Broszormenyi-Nagy & Spark (1973, cited in Chamorro, 2004:68) defined a process of *parentification* or *role reversal* (child as parent or child as parental friend) within the family system. This can imply decision making for the parents, or acting as a parent to disabled siblings. 'Parentification' also raises the importance of a systemic approach to children as caregivers emphasizing the role of providers and givers of support as well as recipients (Earley & Cushway, 2002).



siblings have been referred to as '*auxiliary parents*' (Pollack, 2002), '*parentified child*' (Earley & Cushway, 2002), or '*sibling-carers*' (Dew *et al.*, 2004). In particular, non-disabled children have been identified as '*young carers*' in recognition of the help that they offer the family in caring for their disabled sibling, which is considered additional to the help that may be expected or assumed within a family where there are no disabled children. (Burke, 2004:67-68). But other researchers have found that siblings of disabled children still regard their parents as the main carers (Connors & Stalker 2003; Harland & Cuskelly, 2000). Not all siblings of disabled or chronically ill children can be considered 'young carers' in terms of the varying levels, types and ranges of responsibilities they assume. But Burke & Montgomery (2003) found three patterns of shared care (with parents) by siblings in the UK: i) requested by parent, ii) spontaneous care as 'second nature' and iii) specifically to relieve pressure on parents. Tozer (1996) also found that siblings of disabled children have dual roles in i) caring for their disabled siblings and ii) supporting their parents. And in an American study, Baumann *et al.* (2005), found that siblings who were older than their disabled child described their own roles as 'filling in' while their parents were not around (p.55).

These findings are consistent with those of Smith *et al.* (2000), whose study in the USA found that siblings were more likely to provide affective or emotional, rather than instrumental or direct practical, support. Dew *et al.* (2004:177-178) also argued that siblings' caregiving generally involves social contact and recreational activities, and in some instances '*standing in*' for their now deceased parents in administering financial and consent arrangements. Hannah & Midlarsky (2005) found that American siblings of 'mentally retarded' children engaged in higher levels of perceived emotional support and custodial care but not information giving or tangible aid.

Since the early research of Aldridge & Becker (1993a) in the UK, there has been a vast amount of research into children known as young carers (e.g. Aldridge & Becker, 1993a, b; 1994a, b; 1996a, b; 1998; 1999; 2003; Becker *et al.*, 1998; Dearden & Becker 1995; 1996; 1997; 1998; 1999; 2000; 2004; Butler & Astbury, 2005; Warren, 2007; Banks *et al.*, 2001; Stalker, 2003; Newman, 2003; Thomas *et al.*, 2003).

The responsibilities and position within the family may place heavy burdens on children who act as caregivers (Becker, *et al.*, 1998; Becker, 2007). The burden may be

aggravated when the caring tasks are perceived as unpleasant, interfere with the children's own social activities or where their contribution is taken for granted. Positive aspects of caring responsibilities, however, include the development of altruism, practical skills, maturity, close attachments and relationships (Becker *et al.*, 1998; Dearden & Becker, 2000; Aldridge & Becker, 2003; Aldridge, 2007a). Young carers may experience psychological and emotional problems including stress, isolation, social exclusion, stigmatization, problems at school (including poor achievement, bullying, school absence), lack of time for play or leisure activities, lack of recognition, praise or respect for their contribution, problems with transitions to adulthood, conflicting relationships with family and friends, and threatened self-image (Aldridge & Becker, 1993a and b; Frank, 1995; Cree, 2003; Butler & Astbury, 2005; Dearden & Becker, 1998; 2000; 2002; 2004; Underdown, 2002; Early *et al.*, 2006; Pakenham *et al.*, 2007; Earley *et al.*, 2007; Aldridge, 2007a).

The concept of 'young carer' originally focused on children who actively cared for their (disabled or chronically ill) parents (e.g. Aldridge & Becker, 1993a; 1994a; 1999; Becker *et al.*, 1998; Dearden & Becker, 1995; 1997; Newman, 2003). However, Becker (2000:378) proposed the following definition of 'young carers':

Children or young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would normally be associated with an adult. The person receiving care is often a parent, but can be sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.

Becker (2007) argues that "this operational definition allows a distinction to be drawn between children who are involved in significant, substantial or regular care, many of whom will take on care responsibilities at the early age, and 'those children who, as part of their routine daily lives and roles, may be involved in some aspects of caring but at a level which is neither substantial nor regular, and does not have outcomes that are unduly negative, damaging or restrictive to children themselves'" (p. 26).

However, different definitions of 'young carer' are offered in current legislation and guidance in the UK. For example, the *Carers' (Recognition and Services) Act 1995* uses the definition, 'Children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis'. The Carers National Association (now Carers UK) defines a young carer as anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of someone who is ill, has a disability, is experiencing mental distress, or is affected by substance misuse (Carers UK, 2005).

There is no standard definition of the term 'young carer' and the concept of 'young carer' is contested. Those writing from a disability rights perspective (e.g. Keith & Morris, 1995; Olsen, 1996; 2000; Olsen & Parker 1997; Morris, 1997) argue that the young carer discourse: i) fails to identify social conditions and family dynamics ii) fails to listen to parents' accounts, iii) perceives disabled parents as inadequate, iv) fails to make clear distinctions between the caring activities of children who are described as young carers and those who are not, v) has failed to provide sufficient empirical data, and vi) lacks broader comparative research with other children not described as young carers. For instance, Keith & Morris (1995) argued further that the young carers literature creates a false dichotomy between the young carer and the cared for, ignoring their disabled or chronically ill parents' own roles and contributions to caring, and undermining disabled parents' own rights. They also identified the failure to distinguish between different types of caring and sharing responsibilities undertaken by young carers and by children not perceived as young carers. Olsen & Parker (1997) similarly argued that "without analysing 'young carers' alongside other children in stressful situations, it is not possible to talk of 'young carers' having lost their childhood" (p.125). Banks *et al.* (2001:800) have summarized the young carers and disability perspectives debate as follows:

young carers research has prompted services to be developed in the form of groups and clubs with children as the primary clients. This is in keeping with a children's rights perspective, treating children as individuals, rather than hidden in the family. However, the disability rights perspective suggests that children's needs may be better addressed through services which empower their parents.

Young carers should not be seen as a homogenous group and not all children with disabled or chronically ill family member have parental responsibilities. But younger carers are often invisible children (Banks *et al.*, 2001). Children who have care responsibilities within the family differ in age, gender, ethnicity, co-residency, birth order, power, socio-economic status of the family, informal and formal support networks, the nature and severity of the illness or disability, and the level of dependence or independence of the person being cared for (e.g. Dearden & Becker, 1998; 2004; Jones *et al.*, 2002; Aldridge & Becker, 2003). Dearden & Becker (1998, 2004), for instance, report changing patterns of caring tasks performed by young carers over time in the UK, with an increase in emotional support and supervision and a decrease in personal and intimate care (that are more widely provided by formal service providers). Becker's (2005) comparative review of studies of young carers in Australia and the UK identifies factors that can push or pull children into undertaking unusual levels of care for family members, including the nature of the disability/illness of the person requiring support, the degree of attachment between them, as well as family structure, co-residency, socialisation, low income, a lack of choice and alternatives, gender, religion and culture.

Although some studies have examined the caregiving experiences of children across cultures and countries (e.g. Becker, 1995; 2007; Becker *et al.*, 1998; Shah & Hutton, 1999; Katbamna *et al.*, 2004; Robson, 2000; 2004; Robson *et al.*, 2006; Chamorro, 2004), Jones *et al.* (2002:10) have argued that there is little recognition of children's caring roles in terms of culture. Although ethnicity may not always be to the central way to understand children's caregiving experiences, moral identities and obligations may be the most important 'key' to understanding children's caring roles across cultures (see for review Mills, 2003). In many societies, primary caregiving among siblings is a normative expectation (Hodapp *et al.*, 2005). In the USA, Horwitz & Reinhard (1995) explored ethnic difference in relation to caregiving duties (involvement and responsibilities of caregiving) and the burden (the consequence of caregiving activities) of caring for their mentally ill family member. They found that Black siblings had higher caregiving duties and a lower caregiving burden than White (p.146). However, Robson *et al.* (2006) reported that young people in Lesotho, Tanzania and Zimbabwe who devoted considerable time and energy to caring for sick members of their households in a context of HIV/AIDs, experienced a burden beyond that associated with

normative expectations surrounding children's contributions to the maintenance of households via domestic chores. In these cultural contexts, characterised by poverty and lack of formal service provision, the prime sources of assistance in times of illness and impairment are the family, extended family, clan or kinship system. Becker (2007:24) has also argued that in almost every industrialized Western country, unpaid caring within the family has rarely been conceptualized or discussed as *work*. Rather it has been referred to as 'informal' or 'unpaid caring'. In non-Western countries, children's caregiving is regarded as routine within the family, and little policy attention or professional services are provided to support children (e.g. Robson, 2000; 2004; Robson *et al.*, 2006 (African), Jang *et al.*, 2006 (Korean), Lobato *et al.*, 2005 (Latino American)). According to Becker (2007) international variations in response to young carers ('advanced', 'intermediate', 'preliminary' or 'emerging') are related to social policy and service developments. In this sense, Korea would be at a *preliminary stage of response*<sup>11</sup> with no specific legal right and little official, professional or public recognition of the specific role and position of children who are main caregivers in marginalised families that go beyond 'normal' expectations of children's caregiving within families.

Overall, the literature on young carers highlights: i) the importance of taking into account not only the nature of children's caregiving, but also the actual or potential impact it has on their well-being, ii) problems in conceptualizing the nature of 'children's caregiving' within/across families and iii) the variations in time spent caring and the range of caregiving activities by children.

#### **2.4. Children Affected by Sibling Disability: the New Sociology of Childhood**

The 1990s saw new sociological developments in theorizing childhood set against past theories of child development. According to the new sociology of childhood, children

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<sup>11</sup> In Korea, very limited number of children in child-headed households (total 2,086 households in 2006) was identified as carers (KNSO, 2007:4). They receive the beneficiaries of the livelihood protection and health aid schemes. They also receive financial support for their education and clothes.

are no longer seen as passive objects owned by their parents, but social actors in their own right, contributing in various ways to their families and their communities (Alderson 2000; Christensen & Prout, 2002; Corsaro, 1997; Hendrick, 2000). A central argument of this perspective is that children are seen as independent and autonomous being rather than dependent and subsumed within the family as passive recipients of parental care (Corsaro, 1997; Thorne, 1993). This recent theoretical perspective emphasises the importance and validity of children's own accounts of their experiences.

Despite developments that focus on children's own experiences, siblings of disabled children have been largely ignored within research agendas. Sanders (2004:128) argued that research on the impact of a child's disability on his or her siblings' growth and development generally ignores the child behind the disability, and gives little consideration to effects on siblings of their disabled brother or sister. Research has tended to focus exclusively on the impact of disability per se, being seen to have a powerful influence on families throughout the life span, so that the disabled *child* is easily marginalised (Shakespeare, 2005:140).

In many previous studies of the siblings of disabled children (see section 4.2.), data have been largely generated through adults' perceptions of children's adjustment and relationships rather than by the children themselves (e.g. Hastings, 2003a; Mandleco *et al.*, 2003; Pilowsky *et al.*, 2004; Verté *et al.*, 2003; Mulroy *et al.*, 2008). Other studies, however, have focused on children's own experiences and accounts of the effects of living with a disabled sibling (e.g. Pit-ten Cate & Loots, 2000; Ratcliffe, 2003; Baumann *et al.*, 2005; Davis & Salkin, 2005; Rampton *et al.*, 2007) or a sibling with chronic illness (e.g. Nolbris & Hellström, 2005; Hutson & Alter, 2007). Connors & Stalker (2003, 2004) drew attention to siblings' perceptions of impairment, disability and difference, in interviews with 24 siblings of disabled children, aged 6 to 19. Most siblings were very aware of their brother or sister's impairment, but the majority did not see that as making their disabled siblings different. Dodd (2004) attempted to communicate with siblings of disabled children, all of whom belonged to sibling support groups, about: i) their feelings of having a brother or sister with a range of special needs, ii) their views about their disabled siblings, and iii) the impact this has had on them and their families. Although the children's responses were mixed, it

became apparent that the siblings of children with autism and challenging behaviours tended to express more negative views. The Brazilian study conducted by Marciano & Scheuer (2005), using questionnaires completed by siblings, showed greater negative impact on quality of life among 7 to 11 year olds with autistic siblings than the siblings of children with speech disorders.

Houtzager *et al*'s (2005) study conducted in Holland between 1998 and 2001, compared accounts of sibling well-being given by parents and siblings of paediatric cancer patients at 1 month (83 siblings aged 7-18) and 2 years (57 siblings) after the diagnosis. They found that, in comparison with their parents' accounts, adolescent siblings reported more physical complaints at one month, more emotional and behaviour problems at one month and two years, but higher quality of social life at two years. The authors argued that the assessment of self-reported well-being is especially relevant in healthy siblings, in order to obtain a realistic image of siblings' quality of life. In an American study, Guite *et al.* (2004) showed that younger and male siblings of chronically ill and disabled children reported greater negative adjustment than perceived by their parents. Recently, McGraw & Walker (2007) explored how American White sisters understand themselves and their developmentally disabled siblings. The sisters in their study described themselves as 'good' sisters by portraying their disabled siblings as normal, emphasizing opportunities for moral enhancement, minimizing personal sacrifices, and accepting the gendered nature of family care.

These findings illuminate a wide range of differences in perception between i) adults/parents and children and ii) between children. The new sociology of childhood makes a valuable contribution in identifying the different voices of children with disabled siblings, and offers new understandings and insights into the realities of children's everyday lives, that vary from the perspectives of parents or professionals. The implications for research in using the new sociology of childhood are discussed in greater depth in chapter 4.

## 2.5. Children Affected by Sibling Disability: Cross-Cultural Perspectives

### 2.5.1. A Cross-Cultural Examination at Siblings of Disabled Children

The experiences of 'being a sibling' vary across cultures and societies (Weisner, 1993a; Sanders, 2004:21). Cicirelli (1994: 8-9) has noted that the definition of 'sibling' varies from culture to culture:

In industrialized societies, siblings are identified by genealogical or biological criteria, where full siblings have two biological parents in common and half siblings share only one biological parent. ...In non-industrialized societies, siblings may be defined by extension of the term to certain types of blood kin, or by classification on the basis of criteria other than genealogical criteria alone.

Weisner (1993b), highlights cultural variations in normative expectations of sibling behaviour. For example, sibling relationships in South Asia are characterised by dutiful obligation, while in White North America they depend on individual circumstances. Normative expectations of sibling involvement and influence in South Asia confer important roles within sibling relationships as they are expected to participate in important matters and decisions of one another's lives, unlike North America where siblings follow more individualistic paths (see Table 2-2).

**Table 2-2** A Comparison of Sibling Relationships in South Asia and North America

South Asia	North America
Strong sibling solidarity throughout life	Separate adulthoods
Collective use of resources	Individualistic approach to use of resources
Active sibling involvement in key decision making and life events	Sibling involvement in key decision making and life events not considered important
Strong active caretaking roles	Complementary care taking roles
Dutiful obligation	Individual choice

(Derived from Weisner, 1993b)

Cicinelli's (1994) work on siblings in non-industrialised and industrialised societies



found that siblings in non-industrialised societies have clear sets of obligations to one another while in industrialised societies these are subject to greater parental and personal choice.

Gaps in research limit our understanding of many aspects of the experiences of siblings in different cultures. For example, the experiences of siblings of disabled children differ depending on the availability of welfare services outside the family. But most published research on the experiences of siblings of disabled children has focused almost exclusively on middle class White families in Europe, Australia and North America. These include the UK (Hastings, 2003b), Australia (Cuskelly & Gunn, 2003), Canada (Fisman *et al.*, 1996, 2000; Kaminsky & Dewey, 2001), Sweden (Bägenholm & Gillberg, 1991), Belgium (Verté *et al.*, 2003), and Israel (Pilowsky *et al.*, 2004).

Only a few studies have explored the complex experiences of non-White siblings of disabled children. Wang & Martinson (1996) explored behavioural responses of forty-five healthy Chinese children (aged 7 to 16) in Taiwan to siblings with cancer in the family and examined the factors that may contribute to the presence or absence of behavioural problems in these siblings. Using a 12-month longitudinal data set, they found that healthy Chinese siblings, influenced by cultural values of Familism and Confucianism, showed significantly more behaviour problems and fewer social competence behaviours than a standardized normal Western population. They suggest that professionals, especially nurses, are in a strategic position to help Chinese families maintain their family units and promote cohesion in families living with children with special needs. Ishizaki *et al.*, (2005) found that the psychosocial status of Japanese children with disabled siblings, and their mothers, was significantly poorer than that of children and mothers with no disabled child in the family. Disabled children are usually obliged to live with their families in Japan where mothers are responsible for both medical and nursing care. As a result, the psychosocial status of their siblings was related to difficulties of integration into the community, lack of parental time, or jealousy and resentment toward the disabled child. Lobato *et al.*'s. (2005), American study of forty matched healthy Latino and non-Latino children (ages 8–14 years) of developmentally and physically disabled siblings used interviews and questionnaires to assess siblings' knowledge of, and adjustment to, their siblings' disability. Although Latino and non-Latino children did not have different cultural beliefs regarding the

cause of their siblings' disabilities, Latino children had significantly less accurate information about their brother or sister's disability and poorer psychological functioning and adjustment than non-Latino children. These negative effects were related to 'socio-demographic stress' associated with low socioeconomic status, immigration and migration, and minority status, and authoritarian parenting styles. While this may extend children's respect for parental authority it also inhibits children's verbal expression about emotionally charged topics. Personal sacrifice for the sake of disabled siblings may be particularly forceful among Latino families given the strong emphasis on positive family relationships and socialization pressures against direct expressions of emotional conflict within the families.

In Korea, Eom's (2004) study of 119 children with a range of disabled siblings found that the average general level of stress among siblings was 2.19 on a scale of 1-4. But the average level of stress associated with social life (2.48) was higher than individual life (1.93) and family life (2.15). Eom argues that this finding is linked to strongly negative attitudes to disability in Korea and the impact that this is likely to have on the siblings of disabled children in forging social relations outside the family. Other literature (Ahmad, 2000; Ali *et al.*, 2001; Hussain, 2003; Blacher & McIntyre, 2006) reinforces Eom's argument that negative cultural images of disability often lead to negative experiences for all members of the families of disabled children. The majority of research studies on autistic children and their siblings in Western countries have focused narrowly on restricted outcomes such as the psychological impact of having an autistic brother or sister (e.g. Yirmiya *et al.*, 2001; Bauminga & Yirmiya, 2001). Our knowledge is even more limited in relation to the experiences of siblings of autistic children in different cultural contexts.

I argue that different cultural and societal values are likely to lead to different types of effects of having a disabled sibling, although the impact of cultural values is also influenced by processes of modernization and globalization. It is important, therefore, that knowledge of the impact on children of living with a disabled sibling is extended both geographically and culturally.

### 2.5.2. Siblings in Korean Culture

Understanding sibling relationships in Korean culture require an understanding of i) wider family structures and ii) the nature of interpersonal relationships within Korean culture. Korean culture is inextricably tied to values of Confucianism and Familism characterised by filial piety<sup>12</sup> (known in Korean as *Hyo*), obedience, the importance of the family as the main unit of socialization, hierarchical relations, and patriarchal domination (Kweon, 1998; Park, B.J., 2001; Chung, B.H., 2001). A strong sense of familial care and obligation is central to Korean cultural values (Park & Huebner, 2005:445). The emphasis on family harmony<sup>13</sup> is maintained and reinforced through patriarchal and hierarchical relationships.

Figure 2-4 shows a typical extended Korean family structure in traditional Korean society. Until the recent past, three-generations-under-one-roof was considered to be a basic family unit. The grandfather was the head and represented the family. The grandmother was responsible for managing the household, socializing her daughter-in-law to respect her son, and ensuring grandchildren were properly raised. The oldest son inherited his father's property and power and become the representative of the family. Similarly, the grandmother passed her role and responsibility to the wife of the oldest son. The life of a daughter was considerably different from that of a son. When sons got married, they stayed in the father's family home and carried on the family name, but when a daughter got married, she left her family and became part of her husband's family (Kim & Hoppe-Graff, 2001). With sharply differentiated gendered roles, the father as head of the family had authority to control family affairs, regulating relationships among family members and financially supporting the family. The mother was responsible for caring for children or elderly parents, and managing household affairs. The Korean family was based on strong intra-familial bonds and filial piety (Cho & Kim, 2006:946). In this cultural context, the stability of Korean society was based on unequal roles between genders (Park, Y.R., 2005), and child care responsibilities lay with women, especially mothers, and girls, particular older sisters.

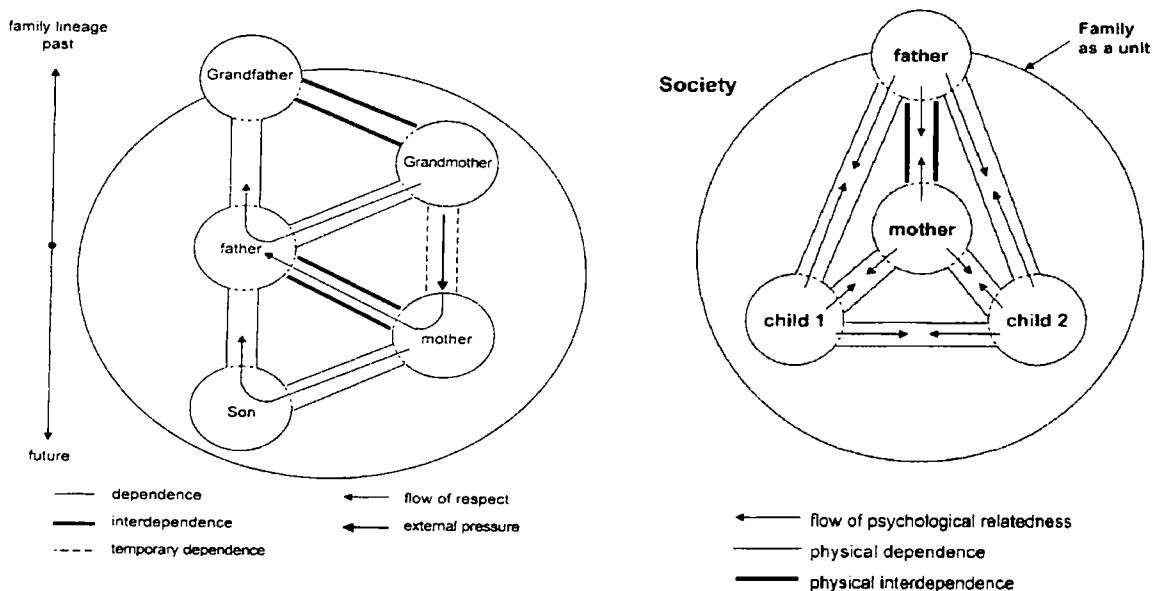
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<sup>12</sup> Filial piety involves respect for the parent, filial responsibility, harmonization of the family, repayment of debts to the parent, affection to the parent, and sacrifice for the parent. (Sung, K.T., 1998a).

<sup>13</sup> Koreans believe that if they follow the family rules, their family will always live in peace and happiness (Park, W., 2006:132)

Figure 2-4 also shows a contemporary nuclear Korean family transformed by the weakening of ethos of Confucian familism (Park, T.H., 2004). Explosively rapid economic transformation and social change affecting family structures and values have altered the traditional value placed on the family (Hyun, K.J., 2001; Kim & Finch, 2002). But despite these transformations, family-centredness, emphasizing familial bonds, love, *Jeong*, reliability, sacrifice and happiness still seem to act as positive reinforcing factors (Yang & Hahn, 2002; MOGEF, 2006). In particular, Korean family members continue to sacrifice their personal priorities for the sake of the whole family's success and achievement in society (Chang, 2003). Such sacrifice continues to be primarily based on filial responsibility, espoused by values of Confucian familism.

**Figure 2-4** Model of Traditional Extended Korean Family (left) and Contemporary Nuclear Korean Family (right)



(Cited from Kim, U.C. (2001) *Ethnography of Korean People and Culture*. pp.262, 271)

Figure 2-4 shows that contemporary family structures have much in common with traditional structures although grandparents no longer play such a significant role in family. Fathers remain at the head of the household with mother responsible for raising and educating children. But Park, B.J. (2001) has argued that patriarchy has diminished as the pressures of working life have increased, and fulfilling the patriarchal obligation to provide for the family has assumed a much higher personal burden since the national financial crisis of 1997. The parallel growth of women's participation in the labour

market has created growing tension between women's increased individual economic power and their traditional subordination to husbands and families-in-law. Wives and mothers are increasingly involved in decisions about family financial management and other family matters including children's education (Kim & Hoppe-Graff, 2001). But despite their growing sphere of influence, Korean wives remain subordinate to their husband's authority (e.g. Sung, S.R., 2003; Jang *et al.*, 2006) and the authority of men over women in Korea continues to take precedence over any authority based on age (Sung, S.R., 2003). These pressures, combined with a lack of formal services, have led to the challenging of filial obligation and filial sacrifice and the clear responsibility for the care for elderly parents or dependent family members has been replaced, in some cases, by the concept of negotiated responsibility (Choi, S.J., 2004; Kim & Min, 2006). According to Yang, O.K. (2001; 2003), current Korean family members interact with each other on a collaborative rather than hierarchical basis. However, the 'family-first' ideology that has led to individual sacrifice for the good of the entire family remains strong and Confucian familist values have not been abandoned by contemporary Koreans (e.g. Yang & Rosenblatt, 2008).

Within the family, Korean children learn to be obedient to older family members by adopting values of *Woori* (collective 'we'-ness) (Farver *et al.*, 2000:587-588), and sacrificing individual values surrounding 'I' (Lee *et al.*, 2006:654). *Woori* embodies collectivism and familism. It is developed and practised through collective and shared activity (Kim, S.H., 2003), consolidated through affective bonds, known as *Jeong* (Choi & Choi, 2002), and conveys notions of 'oneness (togetherness)' or 'sameness' within a community, group or family.

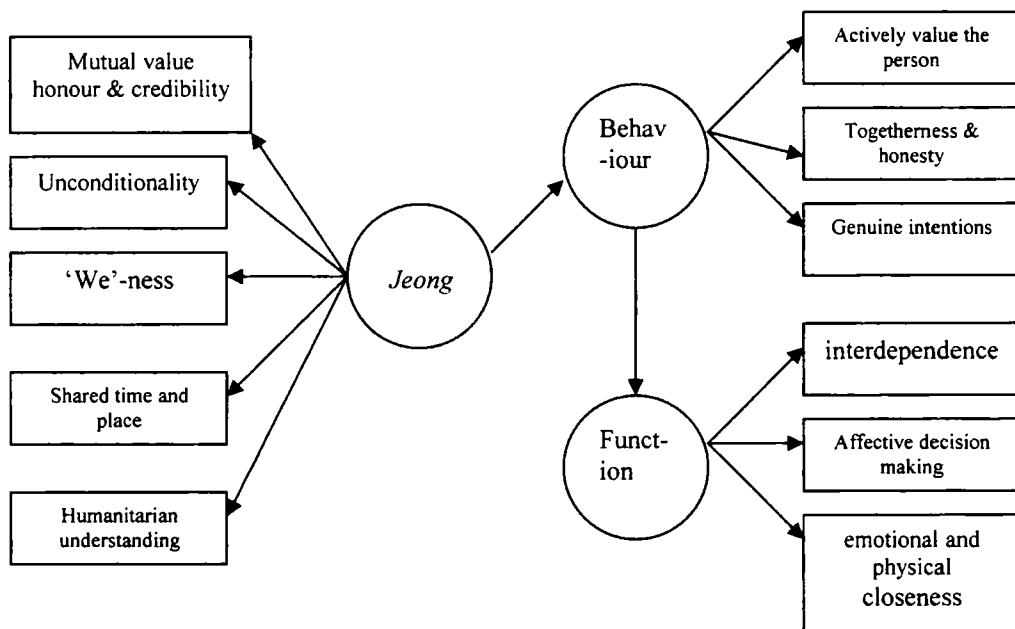
The higher value placed on interdependence and collectivism than on autonomy, independence, privacy, and individualism, has led to a distinction being made between *Woori* and 'others'. Through the development of *Jeong* within *Woori* Koreans became members of a cohesive group at home or work but others without *Woori* can be rejected (Choi & Lee, 1999).

There is no direct translation for *Jeong* in English. Figure 2-5 is designed to clarify the meanings of *Jeong* by introducing its characteristics and depicting its structure, behaviours and functions. *Jeong* aptly describes one of the most fundamental human

emotions governing interpersonal relationships in Korea (Kim, Y.R. 2002; Park, T.H., 2004). Through long contact, individuals come to acquire both good and bad feelings towards a certain individual or objects. *Jeong* encompasses positive and negative affective characteristics such as unconditionality, familiarity, intimacy, depression, anger, and anxiety between people within the same *Woori*. As Kim, S.H. (2003) explains:

Throughout long contact, people come to acquire both good and bad feelings towards a certain individual. Koreans often observe that they have both a '*miunjeong*' (arising from feelings of hatred) and '*gounjeong*' (arising from soft tender feelings). It is interesting to note that the term *Jeong* encompasses the concept of developing feeling of *Jeong* even through a feeling of hatred (p.111).

**Figure 2-5** The Relationships between Structure and Expression, and Function of *Jeong*



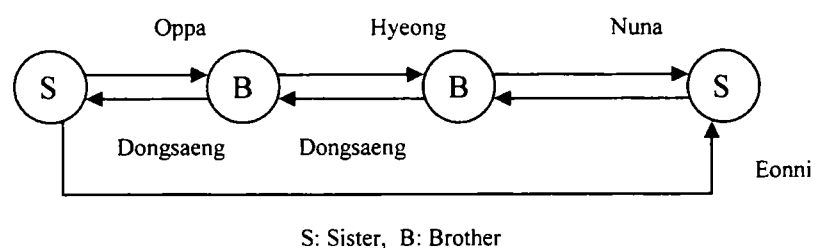
(Derived from: Choi, S.C. (2000) *The Psychology of Koreans*)

There is a Korean saying '*Jeong is deeper than love*'. Koreans believe that love as emotion or feelings may easily change into hate. *Jeong* cannot be manufactured or changed easily, but it endures throughout people's lives (Yang, I.J., 2006) shaped through meeting, intertwined affection, separation and longing (Lee, D.W., 2002). *Jeong* is multifaceted and lies at the heart of relational dynamics between family members. Within the '*Jeong-related*' interpersonal context, the core characteristics of

the Korean family are identified as *Woori*, sameness and oneness (Choi, S.C., 2000). Unlike wider hierarchical family relationships, *Jeong* and *Woori* are not determined by age, gender or gendered family role but by culturally prescribed roles and quality of relationships.

Within this context, the values of Confucian familism continue to prescribe the principles for important interpersonal relations, including those between: parents and children, older and younger brothers and sisters, husbands and wives. Wisdom, responsibility, and benevolence are still bestowed by, for example, parents, older brothers and fathers with obedience, loyalty, and respect being shown by children, younger siblings and wives (Hyun, K.J., 2001:206). Following this cultural code, Korean siblings are ascribed normative roles and responsibilities according to age and gender. Figure 2-6 shows i) how Korean siblings signify distinctions of age and gender through the use of specific terms and ii) the traditional lines of authority and respect. *Hyeong* is the title that younger brothers give their older brothers. *Oppa* (elder brother for younger sister), *Nuna* (elder sister for younger sister), *Dongsaeng* (elder sibling for younger sibling) signify birth order and relationships of authority. For example, respect must be shown to elders. Younger siblings do not address older siblings by their given names.

**Figure 2-6 Model of Korean Sibling Relationships**



(These siblings are increasing in age from left to right)

The first son or daughter is socialized to provide material and emotional support for younger siblings at an early age. Traditionally, exchange of roles and sharing power between older and younger children or boys and girls were not encouraged. Generally, male older siblings have more power and authority. But they also have greater

responsibility to care for their younger siblings and, in response, younger siblings are expected to respect their older siblings regardless of any other considerations.

Older siblings should set good examples for younger siblings and younger children should follow these examples. Older siblings play an important role in raising younger siblings and hold strong responsibilities involving discipline, care and protection. Respect for older siblings continues to be expected and reinforces the continuing concept of filial piety in the Korean family (Tamai & Lee, 2002).

## **2.6. Conclusion and Research Questions: what we know and what we do not know.**

Research on the siblings of disabled children has received increasing attention in recent years. The literature contains multifaceted information focusing on the emotional, behavioural, and relational aspects of the lives of siblings. But findings about the experiences of siblings of disabled children lack consistency.

The first part of this literature review indicated that much of what is known about siblings of disabled children focuses on problems, deficits and negative impacts with limited studies reporting positive or mixed effects. The range of dynamic variables (sibling, parental, family and contextual variables) included in different studies makes comparison difficult and the effects on siblings of living with a disabled child remain elusive both empirically and conceptually. As Stoneman (2005:339) has argued, research on siblings of disabled children is characterised as being 'theory-free'.

The second part of the review, in which siblings of disabled children are conceptualised as caregivers, highlighted the invisibility of such siblings. 'Children as caregivers' covers a large range of possible scenarios (Banks *et al.*, 2001:811) and identifying child carers is very complicated because the impact of their caregiving roles and activities is dependent upon a wide range of factors in differing circumstances. Although we cannot assume that the presence of a disabled brother or sister will inevitably result in their siblings adopting caring responsibilities, the presence of a disabled or chronically ill



sibling is found to be associated with greater caregiving responsibilities than for children with normally developing siblings.

The third element of the review focused on children as social actors within the new sociology of childhood. The literature suggests that listening to children's own accounts of their experiences of having a disabled sibling can reveal distinctive notions about their own perceptions of the impact of disability on their identities and their lives.

Finally, a cross cultural perspective showed that most research on siblings of disabled children has been conducted with white, Euro-American and Australian, middle class families. Exploring the literature on cultural difference, I argue that an understanding of the social and cultural construction of what it means to be the sibling of a disabled child is crucial in understanding the experiences of siblings of disabled children in different cultures (see review by Stoneman, 2005; Hodapp *et al.*, 2005).

Despite the insights offered by existing research, there are still notable gaps. I now go on to discuss what we do **not** know about the experiences of siblings of disabled children. Most studies have focused on the psychological effects of disability on siblings. But the ordinary daily lives of siblings have been relatively unexplored. Although autism itself has attracted greater research attention in recent years, this has not illuminated the everyday experiences of children living with an autistic brother or sister. The contemporary focus on children as carers for ill or disabled parents has, similarly, left the experiences of siblings of disabled children under-explored. Although more recent studies have begun to provide children's accounts of living with a disabled sibling, the majority of research about the experiences of siblings of disabled children has been retrospective and based on the accounts of parents or professionals. The result is that we have very little knowledge about the experiences of siblings with autistic children communicated by the children themselves. The final weakness of current knowledge lies in the unbalanced attention paid to sociocultural settings with white Western knowledge, understanding and meaning being privileged. Very limited information is available on the experience of siblings among families of autistic children in non-Western cultures or countries. This gap is especially striking and offers

rich possibilities for extending insights into the worlds of siblings living with disabled children.

It is on the basis of these arguments that I will address the following research questions in an attempt to extend theoretical insights and add to empirical knowledge:

1. What is the meaning of being a sibling of an autistic child in the Korean cultural context?
2. How do siblings portray their autistic brother or sister and their sibling relationships?
3. How do siblings perceive the impact of living with an autistic brother or sister on their experiences of family life?
4. How do siblings perceive the wider social consequences of everyday life with an autistic brother or sister?
5. What are the expressions of vulnerabilities among siblings of autistic children?

## **Chapter Three**

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# **Siblings in Korean Disability Policy and Practice**

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### 3.1. Introduction

A Korean survey<sup>14</sup> conducted in 2005 (Byun *et al.*, 2006a) found that 3.9% of the registered disabled population was below aged 18. Of these, 23.2% were developmentally disabled (including autism) (p.161). Korean welfare policy has been strengthened and expanded since the late 1980s and this chapter explores and reviews the literature that focuses on the place of the siblings of disabled children in Korean welfare policy and practice.

In the first section, I briefly review conceptual understandings of disability in Korean cultural and family contexts. In the second section I outline, and offer a critique of, current Korean welfare policies and legislation that have relevance for the siblings of disabled children. This section also makes reference to legislation in England and Wales. The purpose is to provide a point of contrast, not to compare the welfare of siblings of disabled children in these two legislative areas on opposite sides of the world. In the third section, I examine current social supports for disabled children and support services for their siblings.

### 3.2. Conceptual Understanding of Disability in Korean Culture

A number of writers argue that the term ‘disability’ can be deployed differently across cultures and countries (e.g. Ingstad & Whyte, 1995; Jenkins, 1998; Dalal & Pande, 1999; Brooks, 2000; Barnes & Mercer, 2003; Rogers-Adkinson *et al.*, 2003; Waltz, 2005; Snyder, & Mitchell, 2006). Cultural beliefs about disability play an important role in determining how disability is perceived. In the Korean context, Grinker (2007) explains that the principle of ‘*Ijil*’ (‘difference’) lies behind popular attitudes to disability. ‘*Ijil*’ carries a negative connotation and implies the ‘unnatural’ and the ‘unwanted’. Grinker argues that ‘the great burden for parents of emotionally or learning disabled children is that they live in a society that places such a high value on sameness and seeks blame of difference’ (p.239). ‘*Ijil*’ is closely related to the notion of shame

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<sup>14</sup> In Korea, a national survey on disabled people has been conducted every five years since 1980 to provide basic information for policy planning, monitoring, analysing and researching, and evaluating.

that is also associated with '*Chemyon*' (face-saving). Choi & Lee, (2002:333) and Lim, T.S. (2002:104-105) describe '*Chemyon*' as a term of collective image or representation that one person values and shares with others. It permeates social values that inform interpersonal interactions and has a prescriptive nature, directing 'acceptable' behaviour in social relations. Losing '*Chemyon*' (losing face) brings shame (Choi, S.C., 2000), not only to the self but to other members of the family and community (Lee, Z.N., 1999; Brown & Brown, 2006). In the family context, saving or losing '*Chemyon*' has a direct connection to the success or shame of the whole family, not simply individual members. Success in individual life is viewed as the highest honour for one's family. But individual failure becomes the worst form of dishonour for the family. In this context, disability (including a wide range of conditions, illnesses and impairments) can bring shame and humiliation and have been depicted as improper or incomplete in Korea (Seo, D.M., 2005:68-69). Cho *et al.* (2003:10) found that Korean mothers of disabled children frequently experienced shame and humiliation when their disabled children misbehaved in public. Che *et al.* (2007) also reported that 89% of 204 Korean parents of mentally/cognitively disabled children were concerned about negative attitudes to disability.

Culturally and socially, Korean society remains less accepting of, and less knowledgeable about, disability than Western society (notwithstanding limited understandings within Western cultures). General societal attitudes toward disability are manifested in stigmatization, indifference, neglect, or even hostility (Lee, H.B., 2000), inhibiting the integration and participation of disabled people in Korean society. Byun *et al.*, (2006a:312), found that 86.7% of disabled Koreans believed they were subject to either discrimination or human rights abuses. In the past, Koreans accepted disability in terms of fatal abandonment or shamanistic thinking. There is also evidence of persistent belief in disability as the result of the geomantic system of topography. This links disability with the choice of inauspicious sites for graves and houses, sins committed in a previous existence, the fault of an ancestor, or a wicked ghost (Erickson *et al.*, 1999; Kwon, M.O., 2000; Kim & Kang, 2003:145). Disability is still associated with 'fatal uselessness', being treated with contempt, and viewed as life-long tragedy (Kim & Kang, 2003; Seo, D.M., 2005).

The terminology associated with disability in Korea reflects and reinforces negative attitudes to disability (Choi & Lam, 2001:81; Choi & Lee, 2005). More respectful terms of '*Jang-Ae*' (disability), and '*Jang-Ae-In*' (disabled people) have been widely adopted as an official term for disabled people since 1990, but the use of offensive terms persists. These include '*Byeong-sin*', and '*Bul-gu-ja*' (related to physical impairment, 'spastic'), '*Ba-bo*', '*Cheon-chi*' or '*meo-jeo-ry*' (related to cognitive or mental impairments, 'retarded' or 'idiot'), and, '*Mi-chin*' ('mad' or 'crazy') (Kim, E.J., 2006:860). Because of the prevailing negative attitudes and terminology, many disabled people, and their families, avoid disability related identities (Kwon, H.S., 2005) and many families with disabled children fail to register their children (e.g. Kim & Kang, 2003).

### **3.3. Siblings of Disabled Children in Korean Disability Policies and Legislation**

#### ***3.3.1. The Development of Korean Welfare Disability Policies and Legislation***

State services for disabled people and their families in Korea must be understood in the context of policies and legislation that have developed since the late 1970s. Influenced by the United Nations international year of disabled persons in 1981, the Ministry of Health and Social Affairs (now Ministry of Health & Welfare) under the military government's '*Welfare State*' developed the *Welfare Law for Mentally and Physically Handicapped* 1981. This concentrates on medical and vocational rehabilitation, and protecting the livelihoods of disabled people (Kim, K.M., 2008:68-69). Under this legislation, the number of institutions and facilities grew significantly and facilities that simply 'housed' disabled people were supplemented with medical rehabilitation, therapies and vocational training (Kim, E.J., 2006:862). However, this legislation benefited disabled people in institutions rather than those in the wider community (Lee, D.S., 2004:239). Disability was narrowly defined, in line with the medical model of disability, as the experience of substantial restrictions in or social life for an extended period due to physical disability, visual impairment, language disability, hearing impairment or mental disabilities. This definition was in official use until 1999 when a classified system was adopted (Seo, D.M., 2005:63).

During the 1980s there were no support services for disabled people to live in the community, and welfare policy focused on institutional 'housing' with an emphasis on social control rather than social care (Kim & Ross, 2007:3). But by the end of the 1980s, welfare policies and services for disabled people were challenged by the Korean disability rights movement influenced by wider, international movements. In 1988, the Korean government began a national register to identify eligibility for benefits. Eligibility criteria were linked to type and severity (on a scale of 1-6) of disability and focused on physical and functional limitations and their effects on disabled people's identities (Kim, E.J., 2006:862).

In 1989, the *Welfare of Disabled Persons Act* was amended and clarified the legal responsibility of government and local authorities for disabled people. Financial support was initiated for disabled children and adults and included social security pensions, medical cost allowance, children's education tuition fee allowance, mortgage, tax exemption. The official term for disabled people changed to '*Jang-ae-in*' from '*Sim-sin-jang-ae-ja*' reflecting a shift in emphasis from the condition (*sim-sin*) to the person (*in*). The role of government was largely limited to financial support and other welfare supports were developed by private and voluntary agencies (Lee, D.S., 2004:238) and still play an important part in the provision and development of social supports for disabled children in Korea.

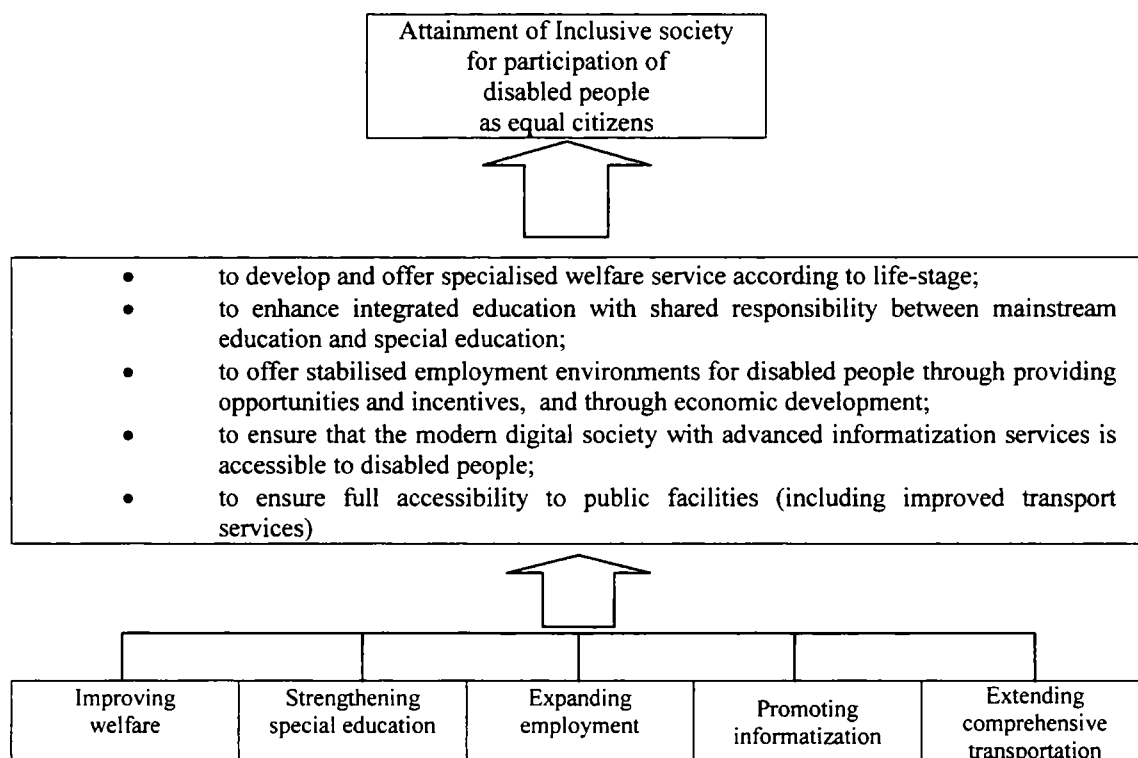
The term 'disability' was broadened by the *Welfare of Disabled Persons Act* (amended 1999), in which a disabled person was defined as unable to ensure by him/herself the necessities of a normal individual and/or social life as a result of physical or mental capabilities. Critically, this definition focused on the idea that disability means having difficulties in activities in daily/social life, as a result of physical disability, brain neurological impairment, visual impairment, hearing impairment, chronic illness, language disability, cognitive disability, mental disability and developmental disability (including autism). The Act also introduced measures designed to prevent discrimination on the basis of disability or disabling conditions. Under Article 7, eligibility for social support was extended to parents and guardians of disabled people.

Despite these developments critics argue that the definition of disability is still focused on physical abnormalities (Lee, D.S., 2004:239) with assessment of disabled children based on 'limitations' rather than 'needs', and eligibility for support being limited to specified problems. As a result, the impact of disability on many children and their families continues to be ignored.

Alongside developing legislation, the *Welfare Coordination Committee for Disabled Persons* (WCCDP) was established in 1996 and drew up the first '5-year Welfare Development plan for Disabled persons' 1997-2002 in cooperation with MOHW, the Ministry of Labor (MOL), and Ministry of Education and Human resources (MOEHR). The Committee's purpose was to establish welfare policies for disabled people and to monitor progress annually. An evaluation by the Committee carried out in 2003 concluded that a fundamental framework of welfare policies had been effectively established to increase the participation of disabled people in society and improve welfare services for disability. These improvements included prevention of disability, extension of disability categories, support of stable livelihoods, extension of participation, availability of rehabilitation services, revitalizing disabled facilities and renovating welfare support facilities (Byun, Y.C., 2002; Lee, J.G., 2002; Yoon, S.Y., 2002). In particular, various welfare facilities (e.g. day-care centre, short-term care centre, respite home, and sign-language centre) in local communities were introduced. But the informal support of family members continued to play a central role in providing long-term care for disabled people, and disability policy remained unresponsive to variations in need based on different types and severities of disabling conditions (Byun, Y.C., 2002). For instance, eligibility for a *Disability Allowance* is strictly limited and even where disabled individuals qualify for financial support this does not meet the true costs of care (Yoon, S.Y., 2002; Lee, J.G., 2002).

A second five year plan (2003-2007) (see Figure 3-1) provided a framework to support a shift in emphasis to encompass equalities and citizenship rights, whilst at the same time improving and extending welfare supports through multidisciplinary networking. The main aim of the plan is to improve the quality of life of disabled people by providing continuous and effective support services (medical, vocation and rehabilitation), and promoting the social integration of disabled people.



**Figure 3-1** Basic Framework for Disability Policy in Korea (2003-2007)

(Derived from WCCDP(2003) the 2<sup>nd</sup> Welfare Development Plan for Disabled Persons. p.7)

Disability services have expanded in terms of quantity and quality, and the percentage of the population registered as disabled has increased from 62.6% in 2000 to 77.7% in 2005 (Byun *et al.*, 2006a:45). Disability benefit has increased yearly from approximately £10 a month in 1991 to £65 a month in 2007 (Yoon, S.Y., 2007). Importantly, the *Disability Discrimination Act 2007* improves arrangements for the identification of discriminatory practices and interventions to maximise disability rights in mainstream welfare services.

Nevertheless, Korean disability policy and practice still confront problems in responding to the various needs of disabled people, including inadequate coverage of health and education services, challenges in enhancing the independence, participation and inclusion of disabled people, and failure to respond to the impact of diverse factors on the experience of disability including conditions giving rise to disability, age, gender, socio-economic needs and family circumstances. The *Welfare Coordination Committee* has not yet achieved its role as a comprehensive coordinating body and has only weak powers to allocate appropriate funding and resources for promoting welfare support and disability rights. Nor has it achieved effective representation in local authorities or disability-related departments of government ministries. The effective coordination of

separate welfare strands for care (*the Welfare of Disabled Persons Act*) and for special education (*the Promotion of Special Education*) remains a continuing challenge as each strand has its own history of development under different ministries (MOHW and MOEHR), and there is a long way to go before effective integration of support systems can be achieved. The disability policy paradigm has shifted dramatically (Kim, Y.D., 2002; Kim & Kim, 2006) from 'protection' to 'disability rights' (Yoo, D.C., 2004). But Koreans continue to see welfare support for disability as an act of kindness or special benefit, rather than an issue of human rights (Kim, E.J., 2006:863). And the disability rights movement continues to raise crucial issues such as cultural invisibility, economic hardship, unemployment, insufficient medical services, lack or inaccessibility of education, inaccessible housing and transportation, institutionalization and human rights violations (Lee, J.K., 2002; Kim, E.J., 2006; Yoo, D.C., 2005).

### 3.3.2. Siblings of Disabled Children in Korean Welfare Policy and Legislation

Despite amendments to Korean welfare policies and legislation to expand support services (see Table 3-1), and to promote equal opportunities for disabled children, there is no policy to address the needs of siblings of disabled children.

**Table 3-1** Korean Legislation with Relevance for Disabled Children

<b>Policies related to Disabled Children</b>	<b>Characteristics</b>
<i>The Convenience Promotion Law for the Disabled, the Elderly and Pregnant Women</i> 1997	secured access for disabled children (among others), to public facilities including buildings and transportation,
<i>The Welfare of Disabled Persons Act</i> (amended 1999)	i) distinguished types and severity of disability; ii) defined responsibilities of government organizations iii) provided for free medical insurance or medical aid, education and vocational training to promote self-sufficiency, and protection of basic human rights through medical rehabilitation programs and welfare centres
<i>The Child Welfare Act</i> (revised 2001)	designed to protect minors and support children in difficult conditions.
<i>The Promotion of Special Education Act</i> (amended 2001)	defined the beneficiaries of special education services, and the scope and level of services and responsibilities of government organizations for disabled people
<i>The Promotion of the Employment of People with Disabilities Act</i> (amended 2001)	instituted a system of incentives to encourage the employment of disabled people
<i>The Child Care Act</i> (revised 2001)	focused on early educational intervention and special education for disabled infants
<i>the Disability Discrimination Act</i> 2007	promoted disability rights, prohibiting discrimination against disabled people.

Although the *Child Welfare Act* (revised 2001) aimed to support ‘*children in need of protection*’ (Article 2), the term ‘in need of protection’ is defined as: children who are in danger, in foster care, or in institutionalised facilities (Nam, S.J., 2002; Do, M.H., 2004). It does not cover other children who may be living within the same families as ‘children in need of protection’. As a result, the siblings of children ‘in need of protection’, may be marginalised and unable to access welfare services. The *Disability Discrimination Act 2007* made new provision for disabled people, including children, but did not address the needs of siblings of disabled children. In contrast, the *Children Act 1989* that has provided the framework for the care and protection of vulnerable children in England and Wales emphasises a child-centred approach with provision to support children ‘in need’ (section 17). This Act emphasises the child in the family context which can include siblings or other relatives, as well as parents, as key figures in a child’s life. The *Guidance and Regulations* (DoH, 1991) refer to both disabled children and their siblings:

The needs of brothers and sisters should not be overlooked and they should be provided for as part of a package of services for the child with a disability. They may however be children in need in their own right and require separate assessment (Vol.6. para.6.4.).

As a result, local Authorities have a duty to provide services to siblings of disabled children, although it should not be assumed that all would be assessed as being “in need” under the *Children Act 1989*. The practice guidance *Assessing children in need and their families* (DoH, 2000a) notes that the siblings of disabled children have often been invisible to professional eyes (para.3.106), and argues that siblings should be on the service agenda of agencies supporting families with special needs.

Returning to the Korean context, the *Welfare of Disabled Persons Act* (amended 1999) also promotes consideration for ‘the protectors’ (or carers) of disabled people:

In formulating and implementing policies for the welfare of the disabled, the State and local governments shall take into account the opinions of parents, spouses and other protectors of the disabled and give special consideration to a life free of concern for the disabled after the deaths of such persons. (Article 7)

This Act does not define ‘*other protectors*’ and does not make any explicit reference to siblings. The *Child Welfare Act* (amended 2000), identifies ‘parents, guardians, foster carers, or persons who have a duty to educate, protect and look after children’ as ‘*the protectors*’ (Article 2. para 3) but fails to identify siblings as ‘protectors’. The consequences of being the sibling of a disabled child remain obfuscated within Korean legislation, although some studies have highlighted the future or present care-burdens of siblings of disabled children (Park, M.K., 1996; Shin, H.J., 2000; Lee, I.S., 2001; Ahn, B.S., 2002).

In England and Wales, the *Children Act 1989* makes provision for siblings who are entitled to an assessment of their needs in their caring capacity:

Many young carers with significant caring responsibilities should [therefore] be seen as children in need. Once a young person is accepted as a child in need the social services department is able to make a wide range of services available to that person to safeguard and promote his or her welfare (S.17(1)).

Further legislation also makes indirect reference to the siblings of disabled children. For example, the *NHS & Community Care Act 1990* emphasises consultation and negotiation, encourages cross-agency collaboration and recommends separate assessment of the needs of disabled individuals and other family members. The *Disabled Persons Act 1986* requires the local authority to carry out an assessment including consideration of the impact of impairment or illness on family members, including any children in the family assuming caring responsibilities. And the *Carers (Recognition and Services) Act 1995* obliges social services authorities to make provision for young carers.

The Korean *Child Welfare Act* and the *Welfare of Disabled Persons Act* were both influenced by United Nations rights-based instruments, the Convention on the Rights of the Child (ratified by Korea in 1999) and the ‘*Declaration of Human Rights of People with Disabilities*’. However, both Acts take a selective approach to supporting disabled children (eligibility criteria confine support to poorer families) and fail to consider the siblings of disabled children (Yoon, C.Y., 2002:26). Strong reliance on the family or informal social networks is the main source of social welfare in Korea (Cook & Kwon,

2007), and children's significant contributions have been 'taken for granted'. Strongly held values of Confucian familism privilege parents' rights over children whose own rights have consequently been ignored, and Korean policy and legislation in turn have marginalised consideration for the siblings of disabled children. They have neither been identified as children in need nor as 'children with rights'. I suggest that these normative cultural expectations increase the vulnerability of siblings, as their own needs are masked by the attention focused on their disabled siblings.

### **3.4. Supporting Disabled Children and Their Siblings in Korea**

Gradual developments in welfare policy and legislation have achieved some growth in support services for disabled people. But deeply embedded values of Confucian familism continue to discourage the use, or provision, of State social welfare services, that are associated with notions of shame, and inability to honour family duties and obligations. In this section, I outline current support services for disabled children and their siblings.

#### ***3.4.1. Financial Support***

Financially, many families with disabled children are substantially disadvantaged. The minimum cost of living for families of disabled children may be higher, and income lower, than those of normally developing children (Gordon *et al.*, 2000; Jenkins *et al.*, 2001; Lukemeyer, *et al.*, 2000; Park *et al.*, 2002; Chung, Y.S., 2005a, b; Byun *et al.*, 2004).

The Korean *National Survey on People with Disabilities 2005* (Byun *et al.*, 2006a: 58) clearly indicated the level of economic and social disadvantage experienced by disabled people and their families. 56.3% of families with a disabled member had an average monthly income of less than 1,500,000 Korea won (£750) while the average Korean family income is 3,019,000 Korea won (£1509.5). The average monthly expenditure of 39.2% of families of disabled people was less than 1,000,000 Korea won (£500). Under the *National Basic Livelihood Security Act (1999)*, 13.1% of families with a disabled

person were defined as being in poverty, twice the rate of families without a disabled member (6.8%). The *National Survey* concluded that Korean families of disabled people experienced higher levels of poverty than those without a disabled family member.

Korean families of disabled children incur considerable expenditure on medical treatment, therapies or special education (Lee & Kang, 1997; Chung *et al.*, 2001; Chung & Han, 2005; Che *et al.*, 2007) For example, Chung *et al.* (2001) found that Korean families of disabled children spent up to 70% of their income on therapy or special education and were unable to reduce this expenditure despite the wider financial hardships they faced. Chung & Han (2005) found that 63% of families of disabled children could not pay for ongoing medical treatments for their disabled children and Byun *et al.* (2006b:239) reported that families of autistic people spent an additional 3,231,000 (€150) Korean won monthly. These studies indicate clearly that having a disabled child in Korea is closely related with poverty.

The *Welfare of Disabled Persons Act* (Article 22), made provision for the support of children with severe disabilities (1-2 grade) living with their families, who registered as having low incomes under the beneficiaries of the *National Basic Livelihood Security Act*. Benefits include allowances related to disability, independent living, education and appliances. Named disabled people (1-3 grade) are also exempt from registration and acquisition taxes when purchasing cars. Other measures such as tax deductions, transportation fee discounts and public facilities fee discounts have been offered to all disabled people. In particular, Article 45 identifies the *Disabled Children Care Allowance* as a major source of financial support for families with a disabled child. Since April 2007, this cash benefit has increased from 70,000 Korean won (€35) to 200,000 Korean won (€100) monthly for registered low-income families of disabled children. And all families of severely disabled children, regardless of income, receive 150,000 Korean won (€75) monthly. Recently, *Child Development Accounts* (hereinafter CDAs) were introduced for children in poverty, including institutionalized disabled children, to resolve the fast-growing division between rich and poor which has been accelerated by globalization and informatization (MOHW, 2007). As an incentive to save, CDAs provide matched government savings of up to 30,000 Korean won (€15) for deposits made into the CDAs each month. In addition, to help institutionalized

children and orphans to begin to accumulate assets, CDAs allow a 60,000 Korean won (£30) monthly deposit for each of these children, half funded by organizational sponsors and half by the government.

In short, financial support for disabled children is strictly limited to i) registered disabled children in low-income families under the eligibility criteria of the *National Basic Livelihood Security Act*, and ii) severely disabled children (Lee, J.G., 2002), reflecting the selective character of Korean welfare support (Ahn & Lee, 2005).

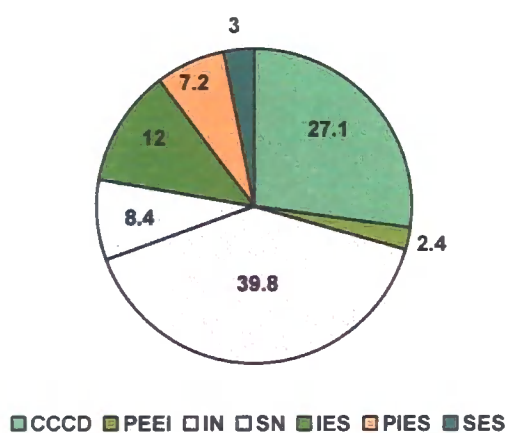
Byun *et al.*, (2006a:70) estimated that in 2005, the average additional direct cost associated with having a disabled child in the family was 155,400 Korean won (£77.7) monthly, while the average additional direct cost associated with having a developmentally disabled (included autistic) child was 323,100 won (£161.55) per month. Despite this difference, the *Disabled Children Care Allowance* has still not been adjusted to reflect the additional direct costs associated with raising an autistic child. Poorer families of disabled children who receive state benefits may not be relieved of financial hardships because financial support does not reflect variations in family circumstances, type and severity of disability (Kang, Y.S., 2004; Chung *et al.*, 2003; Chung & Han, 2005). Moreover, tax reductions, the provision of services and transportation discounts have little impact on disabled children in low-income families (Chun, H.I., 2006). Rather, these families need income-support (Lee, S.W., 2005). Chung & Han (2005) argue that disabled children have not received the maximum benefits to which they are entitled because of a lack of information or problems in making applications. For example, despite available financial support to meet the additional direct costs for medical services including rehabilitation equipment support, medical treatment support, and disability registration fee support, these are difficult to administer, and remain unknown to many families of disabled children. (Chun, H.I., 2006).

Overall, in spite of developments to provide financial support for disabled people, Korean families of disabled children remain at high risk of poverty resulting from additional and ongoing expenses incurred in caring for their disabled children.

3.4.2. Educational Support

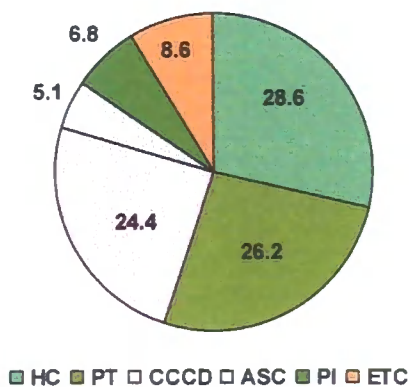
Jang *et al* (2006), in their work with 200 mothers of children under 9 who were disabled physically and developmentally found that 83% attended formal educational facilities and 78.5% also attended additional informal educational facilities. (see Figures 3-2 and 3-3)

Figure 3-2 Percentage of Disabled Children Attending Formal Educational Facilities



CCCD: Community Care Centre for Disabled People PEEI: Private Early Special Education Institute, IN: Inclusive Nursery, SN: Special Education Nursery, IEES: Inclusive Elementary School, PIES: Partly Inclusive Elementary School, SES: Special Education School. (Derived from: Jang et al. (2006) *Status Survey on Caregiving Work in the Family* p.186)

Figure 3-3 Percentage of Disabled Children Attending Informal Educational Facilities



HC: Hospital Clinic, PT: Private Therapy Institutes, CCCD: Community Care Centre for Disabled People, ASC: After School Class, PI: Private Institute, ETC: Unknown Education (Derived from: Jang et al. (2006) *Status Survey on Caregiving Work in the Family* p.189)



Byun *et al.* (2006b) found that the common needs of pre-school age disabled children were for 'care support' and 'special education' while school age disabled children's most common need was 'expanding special education', and disabled adults were most in need of 'income support' 'vocational skills education' and 'special education'. Both these studies suggest that special educational facilities are a crucial need for Korean disabled children.

Special education in Korea has been greatly expanded (see review by Jung, D.Y., 2007) with special schools increasing from 51 in 1977 to 143 in 2006, and special classes in general schools increasing from 350 in 1976 to 5,204 in 2006 (MOEHR, 2006a). Several public organizations and institutions (e.g. Korean Institute for Special Education), with special education assistance teachers, and service centres for special education, have been set up by the Korean government to support special education for disabled children.

Under the *Special Education Promotion Act* (1977)<sup>15</sup>, disabled children have the right to free special education from nursery to high school. Responsibilities of central government and local authorities include the promotion of special education, focusing on inclusive education, individualised education, therapeutic education, vocational education, and career education (Kwon, H.S., 2005). Since 1988, in-service teacher training programmes in special education have been introduced, and teacher training colleges also offer initial teacher training courses for the special education. The *Special Education Promotion Act* (revised 1994) also provides a legal basis for the early education of children with special educational needs in mainstream nursery classes.

There were significant changes in special education in Korea following the announcement of '*Basic Research to Establish a Comprehensive Plan for Special Education Improvement*' (MOEHR, 2006b). In 2007, '*The Special Education Act for Individuals with Disabilities and Others*' was passed providing:

- compulsory education for disabled children from kindergarten to high school,

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<sup>15</sup> The Act is revised intermittently

- early intervention and free education for disabled children under three,
- support in higher and continuing education for people who require special education,
- establishment and operation of Special Education Support Centres, special education related services (e.g. therapeutic education support)

(Kang, K.S., 2007).

MOEHR (2006a) and Park *et al* (2006) found that 37% of disabled children received special education in special schools, 52% in special classes in mainstream schools, while 11% of children with mild disabilities were integrated into mainstream classes of mainstream schools. Nevertheless, due to the restricted categorization<sup>16</sup> of disabilities in special education legislation, many disabled children, especially multiply disabled children, do not receive proper special education (Kim, H.J., 2005) and disabled adolescents and adults often give up higher special education due to the lack of availability (Byun *et al.*, 2006b).

The *Special Education Promotion Act* (Article 2) indicated that disabled students should receive inclusive education in mainstream schools and have an opportunity to meet typically developing children. However, due to the deep-rooted stigmatized belief associated with disability, many disabled children decline the opportunity to receive an appropriate education (Kwon, H.S., 2005; Jung, D.Y., 2002). In Park *et al*'s (2006) study, 75.78% of parents of children with special needs preferred not to access educational services that attracted a label of 'disability'.

The direction of special education policy in Korea is to maximize educational effectiveness for disabled children in mainstream and special education, to give equal opportunities, to create inclusive school environments, and establish special education support systems (Kim, H.J., 2005). The '*5-year Special Education Development Plan*'

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<sup>16</sup> Unlike the Welfare of Disabled Persons Act that categorizes disability by type and severity, the *Special Education Promotion Act* classifies disabilities in seven simple categories: visual impairment, hearing impairment, speech impairment, physical impairment, mental retardation, learning disabilities and emotional disturbance. Multiple disabilities are not classified separately and children with multiple conditions are usually placed in the special school that can respond most appropriately to their principal condition while other disability related needs may be ignored.

(2002-2007) devised by MOEHR, was aimed at promoting opportunities for inclusive education for disabled children and enhancing the quality of special education (MOEHR, 2003). However, the *Plan* emphasises physical inclusion and shows little attention to questions of programme quality or participation (Kwon, H.S., 2005; Yoon *et al.*, 2005) with little consideration for needs-related characteristics, individual differences between disabled children, or necessary curriculum adaptations and modifications (Kwon, H.S., 2005).

Despite government efforts to improve educational support for disabled children, facilities, teachers and resources are still limited. In 2006 only 2.9% of the population of disabled children had been educated at a free nursery in a special school or special class for disabled children (MOEHR, 2006a). Many disabled students are still struggling to enter a school in Korea, and Yoon *et al* (2005) found that 55.8% of students with cerebral palsy and 53.3% of 'mentally retarded' students have experienced rejection by mainstream schools.

### **3.4.3. Social Support**

Caring for disabled children can be exhausting, and creates tensions in relationships within families in all cultures (Dyson, 1996; Trute & Hiebert-Murphy, 2002; Lee *et al.*, 2004; Lee, G.Y., 2005; Shuwa *et al.*, 2006). But it is known that social support services have contributed to the successful adaptation of families of disabled children (Floyd & Gallagher, 1997; Randall & Parker, 1999; Gupta & Singhal, 2005; Shin, J.Y., 2002; Tak & McCubbin, 2002). The concept of social support has been extensively debated and contested. It is multi-faceted and remains difficult to define and measure. For instance, Hupcey (1998) has suggested that social support can be categorised in terms of: i) type of support provided, ii) recipients' perceptions of support, iii) intentions or behaviours of the provider, iv) reciprocal support, and v) social networks. Butt *et al.* (2003) distinguish between: i) emotional (affection, sharing feelings, a sense of belonging), ii) instrumental (tangible or material assistance), iii) informational (knowledge and advice from others) and iv) structural (health, income, living arrangements) support and argue that the type of support may influence how it is received and perceived. As Hupcey (1998) has argued, it is common for descriptions of social support to be vague and

simplistic, rarely specifying types of relationship, interaction between the recipient and provider, or the actual needs for support (p.1232).

In Korea, social support for disabled children is divided into two types: informal support through family, and formal professional support, provided through *Community Care Centres for Disabled People* (hereinafter CCCDs).

Extended family networks play a pivotal role in the care of disabled family members (Jang *et al.*, 2006). Cultural expectations and characteristics of family-centred caregiving are still deeply rooted in Korea. Although the weakness of these traditional sources of support was exposed during the Asian economic crisis of the late 1990s (Cook & Kwon, 2007), family support networks are still central and highly valued. According to a national (sample) survey in 2005 (see Table 3-2), 90.9% of disabled people received support only from family members, and solutions to problems were sought within the confines of the family (Byun *et al.*, 2006a:51). Extrapolating from the findings of this survey, Byun *et al.* (2006a) conclude that large numbers of disabled people are accommodated in the family home, a phenomenon that is reinforced by obligations of Confucian familism and the stigma associated with failure to honour these obligations.

**Table 3-2** The Estimated Number of Disabled People in Korea

(Unit:1,000)

Year	Disabled people at home	Disabled people in residential institutions	Total
2005	2,101,057	47,629	2,148,686
2000	1,398,177	51,319	1,449,496

(Cited from Byun *et al.*(2006a) *2005 National Survey on People with Disabilities*. p.43).

The informal family social network is considered very important not only for interactions but also sharing resources (Lee *et al.*, 2004). For example, Kim & Lee (2003) found that Korean caregivers who have a family member in need were more likely to endure greater sacrifices, through belief in filial obligation, to provide care. The same principle applies strongly to Korean families of disabled children (Donnelly, 2001), except that families of disabled children have more limited family support networks because of the shame associated with having a disabled child (Lee & Kang,

1997). A common consequence of such shame is that families of disabled children are more likely to depend on maternal, than paternal, family members (Jung, S.J., 2004; Lee *et al.*, 2001) reflecting the central role of mothers in child care.

In addition Korean society, with its prejudices, stereotypes and stigma towards disabled children, also contributes to the rejection of formal support services by the families of disabled people (Lee & Kang, 1997; Shin, J.Y., 2002). Receiving care or support from non-family members has been discouraged. Shin, J.Y (2002:109), working with 38 American and 40 Korean mothers with 'mentally retarded' children, examined the effects of culture and social support on maternal stress. Like Jang *et al.*, (2006), she found that the largest proportion of informal support for Korean mothers was from close family members (eg. husband (22%), other children (20%), own siblings (13%), or another mother of a child with special needs (16%). In the case of American mothers, however, informal support was provided by a wider range of sources including own siblings (18%), husband (17%), friend (9%), other mother of child with special needs (9%), relative (9%), neighbours (6%). Significantly, the American mothers had more formal support than Korean mothers, especially emotional and informational support. Shin's findings suggest that Confucian familism is still alive and well in Korea, but is attracting critics who argue that it has encouraged a narrow, insular approach to the care of disabled children, the result of shame associated with seeking support from outside the family.

Moving now to formal or professional support for disabled children, this has been offered by CCCDs, private agencies or special schools. According to Shin, J.Y. (2002:109), the greatest share of formal support in Korea came from special education teachers (39%), private therapists (18%), general education teachers (16%) and doctors (7%). Since the 1980s, the number of CCCDs has increased to 129 in 2005. CCCDs provide various support services (Byun, *et al*, 2005): social-psychological support (e.g. rehabilitation counselling, social adaptation skill, family support including sibling support groups), educational support (e.g. early intervention special education, and inclusive education assistance), medical support (e.g. therapies), job-skill support, community support (e.g. visitation assistance, disability prevention programme) (Kim & Lee, 2005). The CCCDs consist of a 'one-stop' system of comprehensive support

services, requiring attendance and therefore resembling an institutional model of support. This system of support fails to meet the widely ranging needs of disabled children and their families since it lacks close connections with other organizations in the community such as local health centres, day care centres and special education schools, that could provide effective and comprehensive services to disabled children. (Kim, Y.D., 2005a).

Day care support for disabled infants, under school age, is provided in formal care facilities including *Noli-bang* and *Eolini-jib* (Kindergarten) (42.9%), special classes in general care facilities (8.0%) and special care facilities (49.1%) (Byun *et al.*, 2006a:54). However, half of all disabled infants do not receive these support services. For school age children, Byun *et al* (2006a:221) found that at the end of the school day 19.9% of disabled children were left alone at home until their parents returned from work, 37.4% returned home to family members and 18.3% participated in private educational institutions '*hakwon*'. For disabled children with higher levels of need, residential care, group homes, day care centres and sheltered workshops are offered. In 2006, 6,104 children (under 19 yrs) received these forms of institutional care. However, day-care remains rare and services such as respite care and foster care services are embryonic and confined to the private sector. Public residential care facilities may only be accessed by children who are registered disabled under the *National Basic Livelihood Act*. Private residential facilities may be accessed by children who are not registered under the Act but this leaves them open to greater possibilities of abuse as parents admitting their children to private facilities are often required to waive their parental authority (Lee *et al.*, 2003:272). The stigma of having a disabled child, and the greater stigma associated with groups of disabled children, reinforce attitudes of contempt for residential care. These negative social attitudes further reinforce disabled children and young people's own negative attitudes to residential care and Byun *et al.* (2006a:335) found that most disabled children and young people expressed the desire to continue living in their family home.

Despite some expansion in support services for disabled children since the 1980s, current provision remains limited, provider-centred, top-down and relying largely on the private and voluntary sectors (Kim, Y.D., 2005b; Kim & Ross, 2007) where services

attract fees. This exacerbates problems for the families of disabled children in accessing services. It seems clear that Korean social policy continues to rest on value-based assumptions that families will continue to bear the costs of caring for disabled children, largely on their own. I suggest that changing socio-economic circumstances and family arrangements have led to greater involvement of children in the care of, and responsibility for, disabled siblings and, in the following section, I consider the needs of siblings and arrangements for their support.

#### ***3.4.4. Supporting Siblings of Disabled Children***

Studies of living with a disabled sibling in Korea (Shin, H.J., 2000; Kwon, J.O., 2001; Jin, M.S., 2001; Shin, H.Y., 2002; Choi, M.J., 2001; Lee, I.S. 2001; Jun, J.H., 2002; Lee & Kwon, 2002; Min, Y.S., 2003; Seo, M.S., 2004; Koo, J.H., 2007) have focused on psycho-social effects and like studies in other cultures (see section 2.2) reached mixed conclusions that identify varying degrees of stress, burden, regret, guilt, sadness, loneliness, and social interaction, associated with being the sibling of a disabled child. These effects shed some light on the needs of siblings. But more specifically Ahn, B.S. (2002), working with 80 Korean siblings of 'mentally retarded' people between age 9 and 50, found their greatest needs were related to: i) support in caring for their disabled siblings in the present and the future, ii) understanding disability iii) the current home environment and iv) social inclusion. These findings contrast with those of Western studies (Lobato, 1990; Meyer & Vadasy, 1994; Harris, 1994; McHugh, 2003; Powell & Gallagher, 2005), in which siblings' greatest needs have been identified as i) respect and understanding, ii) parental attention, iii) information, iv) counselling, and v) training. Of course, siblings' needs may vary, and siblings of disabled children have different specific needs according to place and time.

A common response to the impact of living with a disabled child has been the development of support groups for siblings (You, H.K, 2002; Kim, H.J., 2004; Kim, S.H., 2004; Burke & Montgomery, 2000; 2003; Evans *et al.*, 2001; Powell & Gallagher, 2005; Lähteenmäki *et al.*, 2004). Studies of sibling support groups indicate common formats including information, recreation, socializing, discussion, activities and games (see review by Kerstein & Gabriels, 2002). The aims of sibling support groups also

have much in common, such as providing a place and time for fun, meeting with other children who have disabled siblings, providing information on disabilities to improve siblings' understanding, sharing experiences encountered and adaptive ways of coping, and encouraging siblings to express their feelings (Lobato, 1990; Meyer & Vadasy, 1994). But there are many different types of support groups for siblings of disabled children in different parts of the world (see Table 3-3) and many differences among sibling support groups. Some include the siblings of children with wide ranging disabilities (Dodd, 2004), while others focus on siblings of children with specific conditions or disabilities (Hwang, B.M., 2003; Smith & Perry, 2004; Naylor & Prescott, 2004). They also differ in the age range of participants, typical number of sessions, length of sessions and group structures.

The role played by sibling support groups can also be varied. First, the counselling type of support group is a direct way to help siblings to express their feelings, but it is not suitable for younger children. Second, a sibling training group can be an effective way of engaging in tutorial interaction with a disabled brother or sister. But only a limited number of siblings can be skilled. Training siblings to become therapists and teachers may inadvertently cause increased conflict between children and may provide an extra burden to siblings. Third, sibling support groups help to enhance positive interaction and to share understanding between children and their disabled siblings or others. But joining support groups cannot directly intervene to reduce stress between children and their disabled sibling or others. Parental involvement is also required. Finally, psycho-educational support groups can enable sibling support networks to give a shared understanding of the impact of disabilities, but do not consider variance in age and type of disability.



**Table 3-3** Example of Types of Sibling Support Groups

Type	Counselling	Training	Social interaction	Psycho-educational support
Author / Nation	Hong (2004) Korea Kim, S.H. (2004) Korea	Shin, H.J., (1995) Korea Hwang, B.M. (2003) Korea	Leem (2002) Korea An & Kim (2005) Korea	Chun (1997) Korea Yang, S.M. (2003) Korea Naylor & Prescott (2004) U.K Dodd (2004) UK Smith & Perry (2004) Canada D'Archy <i>et al.</i> (2005) Ireland
Age of sibling	Elementary school-aged	Infants and Elementary school-aged	A range of ages	A range of ages
Types of Disabled children	Autism, Down's syndrome Learning disability	Autism Speech impairment	Autism, Down's syndrome Learning disability	A range of disability
Duration	8 weeks – 10 weeks	4 days – 2 months	3 months	1 month – 5 months
Programme	Structured Art-based activity Discussion	Imitated Activities Role-Play	Structured Activities Group Activity	In/outdoor Activities Day trip, Group Activities
Aims	i) Encouraging understanding their disabled sibling ii) Giving opportunity to express unexpressed emotions	For disabled sibling, children's tutor role training	i) Having positive attitude toward their disabled sibling ii) Relieve stress iii) Positive self-esteem iv) Enhancing social interactions with others	i) Sharing same experience and information ii) Encouraging supportive environment
Outcomes	i) Expressing negative emotions ii) Decreasing stress iii) More understanding their disabled sibling and parent iv) Increasing positive coping	i) Expanding informal educational support for disabled children ii) Reducing parental burden iii) Promote more positive attitudes and more meaningful interactions	i) Having effectiveness of positive interaction with their disabled sibling and parent ii) Increasing understanding their disabled sibling iii) Receiving supports from others	i) Making supportive network between participants ii) Increasing positive self esteem iii) Understanding family circumstance and their disabled sibling
Limitations	Not suitable for young age children	i) Limited number ii) Increasing burden iii) Producing conflict between children	i) Difficulty in direct intervention between child and their disabled sibling ii) Need parents help iii) Difficulty of connection with community	No consideration of age-related needs

It is evident that attending sibling support groups is of benefit to siblings as discussed in Western literature (Dyson, 1998; Evans *et al.*, 2001; Burke & Montgomery, 2003; Dodd, 2004; Naylor & Prescott, 2004; Burke, 2004) and Korean literature (Chun & Park, 1998; Yang, S.M., 2003; Lee, S.H., 2006). For instance, Chun, H.I. (1997, 2001) found a sibling support programme effective in changing children's behaviour towards their disabled siblings. Kim H.J. (2004) found another sibling support group led to more positive concept of self, and more positive sibling relationships. In particular, an evaluation study of a third sibling support group by You, H.K. (2002), involving a total of 131 siblings of 'mentally retarded', autistic, hearing impaired and multiply-disabled children between aged 10 and 19, revealed that siblings' expectations of the support group focused on 'learning ways to help their disabled brothers and sisters'. Moreover, siblings aged 13-19 and siblings of hearing impaired children expected to improve their relationships with their disabled siblings. Although no firm conclusions can be drawn from these studies, her study does offer hints that sibling support groups have the potential to positively reinforce cultural values of filial responsibility, particularly among adolescents.

In Korea, the few support groups that have developed have a format of day-camps or short-term education programmes (Yang, S.M., 2003). Most these groups (e.g. Chun, H.I., 1997, 2001; Kim, S.H., 2004; Kim, H.J., 2004; You, H.K., 2002) are based on 'Sibshops' developed by Meyer & Vadasy (1994) and are usually managed by voluntary agencies or CCCDs. Decision-making about eligible participants varies from agency to agency, and is likely to rest on criteria set by the provider rather than the needs of each individual child. As a result, many siblings have been excluded (Chun, H.I., 2003). In the UK, sibling support groups have flourished in the last few years, and the need for sibling support is inherent within the Assessment Framework (DoH, 2000b). However, services remain under-resourced, and needs-assessment continues to focus on the disabled child (Burke & Montgomery, 2000; Burke, 2004).

It is now recognized that there is a lack of services for siblings of disabled children across public, voluntary and private sectors in Korea (Chun & Park, 1998; Yang, S.M., 2003). But within the family, the contributions of siblings remain unacknowledged with greater attention being paid to disabled children and their parents.

### 3.5. Conclusion

In this second part of the literature review, I have described the cultural values underpinning attitudes to disability in Korea, traced the dramatic development of Korean welfare policy and support services for disabled people over a short period, and identified remaining challenges in policy, practice and research.

Confucian familist values underpin the enduring role of the family in caring for disabled children with little input from outside sources of help. Negative attitudes towards, and stigma associated with, disabled people are a crucial influence on the lives of all family members. In this context, families still remain the fundamental providers of long-term care for disabled people in Korea.

Although the disability policy paradigm, influenced by industrialization and globalization, has shifted to embrace the notion of disability rights, welfare policy is still based on Confucian familist traditions. As a result, there are tensions between the roles of the state, and the roles and rights of disabled people and their families. But within these debates the siblings of disabled children have been marginalised.

The development of various welfare support services has played an important role in supporting disabled children and their families. But there has been little development of policy, or practice interventions to support the siblings of disabled children whose daily lives remain strongly influenced by principles of filial obligation as part of Confucian familism. The limited services that exist, such as support groups, are valuable but do not appear to take into account the wide variation in needs among siblings of disabled children.

In the following chapter I set out the methodology and methods used to explore these questions, discuss the ethical challenges associated with the research strategy adopted, and outline the methods of analysis used to interrogate the data generated by the empirical study of and by Korean siblings of autistic children.

## **Chapter Four**

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# **Research Design: Visual Ethnography with Children**

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## 4.1. Introduction

In this chapter I present the methodology and methods used to operationalize the research questions, building on the experience of previous research to address the particular challenges in working with children as active researchers. Section 4.2 describes the methodological limitations of previous studies of the siblings of disabled children. Section 4.3 makes the case for the use of visual ethnography as a useful and innovative approach to gaining insights into the daily life of siblings of autistic children. In section 4.4 I discuss the rationale for the involvement of children as active researchers and go on, in section 4.5, to present the experiences and lessons learned from a pilot study conducted in England prior to embarking on fieldwork in Korea. Section 4.6 outlines methods for: i) achieving a sample of siblings of autistic children, ii) the collection, analysis, and interpretation of visual data and interviews with parents, and iii) investigating questions of validity and credibility. The final section, 4.7 is devoted to the complex ethical considerations that inform the study in all its stages. This is not to treat ethical questions as being of secondary importance. On the contrary, it is to ensure that they are given explicit attention as a whole, in addition to their presence at different stages of the study.

## 4.2. Methodological Issues in Past Research

Previous research on the impact of living with an autistic sibling has produced findings that are equivocal or contradictory. Most studies have used psychosocial frameworks based, uncritically, on the hypothesis that living with an autistic sibling will have psychological, if not psychiatric consequences (see chapter 2). Table 4-1 demonstrates heavy reliance on a range of standardized instruments to measure outcomes, such as depression, anxiety and social and emotional dysfunction. The most common approach to research on siblings has been self completed questionnaires with questions derived from an adults' world view. Of particular concern are inconsistencies in the findings of these studies that have raised questions of reliability (Stoneman, 2005; Hodapp *et al.*, 2005) suggesting that different instruments or approaches may be required to capture variations in impact according to complex combinations of variables including age,

gender, birth order, severity of condition etc). However, as Cuskelly (1999) and Hodapp *et al.* (2005) have argued, research on siblings of disabled children continues to be conducted in the same ways using similar methodologies (see Table 4-1).

Moreover, the majority of existing studies have been retrospective or based on parental or professionals' reports, rather than on observations of, or interviews with the siblings, although several researchers have found discrepancies between sibling self-reports and parental-reports (e.g. Glasberg, 2000; Guite *et al.*, 2004; Houtzager *et al.*, 2005; Macks & Reeve, 2007).

Other critiques of quantitative approaches to the study of siblings' experiences include: i) the incomplete picture of the world of siblings of disabled children (Fine & Sandstrom, 1988), ii) inadequacy or inappropriateness where children do not fully understand the questions, or feel intimidated by adults asking the questions (Rampton *et al.* 2007), iii) the 'measurement' of children's lives at a single point of time (Cuskelly 1999), and iv) the inability to capture subtle differences in environmental variables that go beyond simple socio-economic descriptors and are associated with marked differences even between twins brought up in the same household (Hodapp *et al.*, 2005).

Only a few studies have used 'child-friendly' methods such as art-based interviews to seek children's views of daily life with a disabled sibling (Connors & Stalker, 2003, 2004) and there is little information to date on the experience of living with an autistic child from the point of view of the sibling.

A major challenge in conducting my study was the lack of tried and tested qualitative approaches to researching sensitive subjects with siblings of disabled children. The limitations of existing methods suggested a need for an innovative approach that would offer age-appropriate, participant-friendly and participant-centred methods that encouraged free expression without the input or influence of parents or other adults. The study called for the use of inductive methods in order to avoid the pitfalls of a predetermined approach.

**Table 4-1 Example of Measures & Methods of Previous Studies<sup>17</sup>**

Researchers	Year	Measurement tool	Target group	Variables	Method	Results
Mates	1990	The Piers-Harris Self-concept scale The Wide Range Achievement test The Rutter questionnaire for parent, teachers.	5-17 years children and adolescents	Adjustment between sex, family size, performance on achievement, self-concept, home behaviour and school behaviour	Interview & questionnaire	The sibling's performance was not suggestive of needing special intervention.
Bägenholm & Gillberg	1991	Piers-Harris Self-concept scale Parent rating of children's behaviour toward siblings Rutter scale Eysenck Parent personality inventory Observed family stress	5-20 years children and young adults	Psychosocial problem	Interview followed by questionnaire Observation	Siblings of disabled children were more concerned about their future, felt lonely, care burden, behaviour disturbance and had peer problems
Gold	1993	The Children's Depression Inventory The Child Behaviour Checklist	7-17 years children	Depression, Social adjustment Care, Domestic responsibility Gender, age, birth order, family characteristic	Questionnaire	Siblings of autistic boys showed significantly higher on depression than the comparison group, but not on problems of social adjustment. There were no statistically significant gender differences.
Rodrigue <i>et al</i>	1993	Perceived competence scale Pictorial scale of perceived competence and social acceptance Child Behaviour Checklist Marital adjustment scale	19(HFA) 20(D) 20(ND)	Internal or external behaviour problem	Questionnaire interview	Siblings of HFA have more internalizing and externalizing behaviour problem than siblings of ND.
Knott <i>et al</i>	1995	Behavioural Code (Abramovitch <i>et al</i> 1987)*	1-12 years children	Siblings' interaction	Observation Questionnaire (parent)	Interactions of siblings involving autistic children reveal impoverishment. However, all learning disabled children engaged in frequent bouts of interaction, usually directed by their siblings.
Glasberg	2000	The Concept of Autism Protocol	5-17 years children and adolescents	Perspective of autism	Interview	Although accurate in estimating their child's understanding of the definition and cause of their sibling's diagnosis, parents

<sup>17</sup> D (children with Down's Syndrome), HFA (high functioning autistic children), ND (normally developing children)

						tended to overestimate their child's understanding the disorder's impact.
Miller	2001	The Sibling Anxiety questionnaire Behaviour Rating scale	10-16 years adolescents	Acceptance, Hostility, Support Embarrassment, Parent treatment	Interview questionnaire	Specific difficulties in having a autistic sibling were perceived – parental favouritism and concern for their sibling's future
Kaminsky & Dewey	2001	Sibling relationship questionnaire The Gilliam Autism Rating scale Adaptive Behaviours questionnaire Demographic questionnaire	8-18 years children and adolescents	Sibling Relationship	Questionnaire	Sibling relationship in families of autistic children were characterized by less intimacy, pro-social behaviour and nurturance than those of the two comparison groups
Rivers & Stoneman	2003	Family information form The Sibling inventory of Behaviour Sibling Relationship scale	7-12 years children	Family system theory Relationship with marital stress	Self-report inventories & Questionnaire	Families experiencing high marital stress who sought greater support from formal resources external to the family had typically developing siblings who reported a higher level of negative sibling behaviour than families who sought low levels of formal support.
Verté <i>et al</i>	2003	Child behaviour checklist Matson Evaluation of Social skills with youngsters Self-Descriptions questionnaire I & II	6-16 years children	Adjustment Behaviour problem Social competence Self-concept	Questionnaire	Siblings of children with HFA (aged 6-11) had more behavioural problems than control group. Sisters of children with HFA had higher social competence and more positive self-concept.
Pilowsky <i>et al</i>	2004	Weinberger adjustment inventory Vineland adaptive behaviour scale Child behaviour checklist Demographic information Daily hassles and uplifts	-16 years children	Social and emotional adjustment Genetic liability Environmental factors	Interview	Most of the siblings were well adjusted.
Ross & Cuskelly	2006	Child behaviour checklist	8-15 years siblings	Adjustment, problem behaviours and coping strategies	Questionnaire	Siblings of autistic children are at increased risk of developing internalizing behaviour problems.



Ethnography has been employed as an effective method of exploring the social worlds of children (e.g. Eder & Corsaro, 1999; Christensen, 2004; Emond, 2005; Thomas, 2006). Ethnographic research offers an opportunity to understand how children are defined in specific cultural contexts, but also seeks to understand the way in which children's social worlds are shaped and controlled by themselves, as well as by adults (Hardman, 2001; Emond, 2005). Shakespeare & Watson (1998) suggested that ethnographies of siblings are more helpful in developing theories based on children's own perspectives. I identified only two studies in the literature that report the use of ethnographic methods to observe the day-to-day life of children growing up with a disabled brother or sister (Bluebond-Langner, 1996; Davis & Salkin, 2005). These studies reinforce the value of ethnographic methods to 'know' (Briggs & Sharpe, 2004) the daily lives and social worlds of children growing up with autistic siblings.

### **4.3. Choosing an Appropriate Research Methodology: Visual Ethnography**

#### ***4.3.1. Visualizing Everyday Life***

Ethnography is widely understood as an appropriate methodology for seeking representations of everyday life within particular 'cultures' (Vidich & Lyman, 2000; Patton, 2002). Ethnography is concerned with people's behaviours in everyday contexts, rather than under conditions created by the researcher (Hammersley, 1998:2) and is an excellent way of gaining insight into a cultural context or a complex social process (Punch, 2005). Ethnography tries to seek the understanding of the other's world by participating in the research context and making explicit the insider's accounts in the context (Hammersley & Atkinson, 1996) rather than testing hypotheses or establishing relationships between variables (Emond, 2005). In particular, James *et al.* (1998) suggest that using ethnography in research with children might be the most appropriate way to get close to understanding the child's world. Ethnographic research embraces different types of methodological tools such as participant observation and individual and group interviews within the participants' own worlds. However Crang and Cook

(2007:7-8) argue that ethnographic researchers: cannot 'read' their participants' cultures unproblematically; are mistaken in treating culture as pure; and in treating participants as pure, transparent and knowable carriers of cultural codes, in the face of narrow subjective knowledge.

Traditionally ethnography involved the use of observational methods with the use of transcribed fieldnotes to achieve the translation of visual observation into words (Bryman, 2001). However, traditional ethnography relied only on researchers' eyes and memories. This approach was vulnerable to the omission and loss of important 'facts' from the record (Rosenstein, 2002). I also argue that the use of traditional approaches to ethnography rely on adults as observers of children's worlds (James *et al.*, 1998). By contrast, using visual images in ethnography can give rise to 'alternative paths of inquiry' and inevitably a more 'open-ended nature of inquiry' (Banks, 2007:60). Contemporary social life has been recorded visually more than ever before. Visual images are encountered on a daily basis and form a central part of human lives, human communication and human representation. Visual images offer particular views of social actions, and depict people in particular ways. As Mirzoeff, (1999:1) stated: "seeing is much more than believing. It is not just a part of everyday life, it is everyday life".

Compared with traditional ethnographic methods, the use of video/film has a short history in social science research (see Walsh *et al.*, 2007, Banks, 2007). Nevertheless, video is now increasingly accepted as an important tool for observing and recording social life (e.g. Pink, 2001b, Banks, 2001). With developments in digital video technology at the end of the 90s, digital video has been employed increasingly in social research and elicitation techniques (Walsh *et al.*, 2007). Grasseni (2004) defines the use of video in research:

Video recording can serve as a propedeutic element to any in-depth observation, as a tool for refining the ethnographer's attention, for monitoring and aiding the training of the eye. Also, recorded material can be revisited and accompanied by an analytical description and a systematic explanation of specific aspects of skilled vision. (p.16)

Visualizing can be an excellent way to disseminate the hidden worlds of participants which the researcher's eyes may ignore (Walsh *et al.*, 2007). Collier & Collier (1986) also pointed out that video/film allow us to deal with the 'what' as well as the 'how' of an event, and can be interpreted by multiple viewers. In particular, video provides the researcher with the possibility of distance from the data, joint viewing, or reviewing of data (Rosenstein, 2002). As a result, visual ethnography can help to avoid narrow single interpretations of data or selectivity at the time of recording.

Generally, qualitative-based methods can be used to uncover or understand what lies behind any phenomenon about which little is yet known (Strauss & Corbin, 1990). Visualizing has much to do with a kind of seeing that reveals form, pattern, essential nature, and underlying knowledge of the observed world (Suchar, 1997:35). Although the use of visual research is strongly debated, the use of visual materials to document areas of social and cultural life would appear to be straightforward and unproblematic (Banks, 1995). There is evidence from previous research that suggests visual media as a means through which participants can depict and understand their own view (see Rampton *et al.*, 2007). Harper (1998), for example, regards the uses of photography in ethnographic research as 'scientific mode' able to capture information 'too fleeting or complicated to remember or describe in writing' (cited in Emmison & Smith, 2000:29). Lomax & Casey (1998) also suggest that visual methodology is an ideal way to record the minutiae of social life, appropriate for naturalistic study.

Video can give us a more complete sense of who the participants are, acquainting us with the settings in which they function and the activities in which they engage from day-to-day (DuFon, 2002:43). As Grasseni (2004) has suggested, visualizing can contribute to the understanding of other cultures. Visual ethnography can be natural and realistic, even though the visual images would not be understood in the same way by different people. It can offer data about personal experiences, subjective understandings and contextual knowledge surrounding daily lives, including unnoticed details of daily life. In particular, the use of video in ethnography facilitates the recording of all that is within the viewfinder and the spontaneous capture of transitory information both visual and aural (Dant, 2004). Video also enables the repeated observation of non-verbal

communication, actions, gestures to support the analysis and interpretation of interaction (Rosenstein, 2002). Video is perceived to be an effective means of reaching and hearing those lacking a voice in a community. Indeed, several studies involving autistic children have used video as a data collection method (e.g. Ochs *et al.*, 2001, Bernabei & Camaioni, 2001, Receveur *et al.*, 2005). Pink's (2001b) evaluation of ethnography as a methodology includes its potential to experience, interpret and represent culture and society that informs and is informed by sets of different disciplinary agendas and theoretical principles.

The use of visual ethnography in my study is intended to aid interpretation, representation and elicitation of phenomena using the visual device to explore siblings' perspectives on their daily lives. I do not use ethnography simply as a way of gathering data, but also as a device for seeking thorough knowledge of the daily lives of siblings. 'Doing' visual ethnography does not mean just gathering siblings' stories. It means putting them into a wider context and exploring their actual experiences of everyday life as individuals, as siblings, as part of a family and of wider socio-cultural contexts.

Visual ethnography however comes with its own challenges, and care must be taken to maintain data generation methods that are as unobtrusive as possible whilst producing data of the highest quality. This involves careful choice of data collection tools (Bloustien & Baker, 2003) to match the abilities of those involved directly in data collection. In this study, it is the siblings of disabled children themselves who are involved in capturing the experiences and meanings of everyday life and the choice of data collection tool was designed to match their skills and popular choices. I therefore chose to use a personal multimedia player/recorder (hereafter PMP) that facilitated the production of still and moving picture images, and audio recording.

#### ***4.3.2. Visualizing the Self***

Ethnography involves deriving knowledge from the interaction between 'subjects', 'researchers', 'texts', 'experiences', 'words' and 'images'. Traditionally this approach has involved the researcher retaining considerable control and power over the process of interpretation, rather than achieving collaboration between subject and researcher.

Emond (2005:125) argues that ethnography remains a method befitting the exploration of the meanings and constructions held by participants of their social world, but current critical debates would pose the question: 'who should do the video recording?' Dufon (2002) reviews three approaches: the researcher (e.g. Ventres *et al.*, 2006), professional videographer (e.g. Brannen, 2002), or participants (e.g. Bloustien & Baker, 2003; Kindon, 2003).

The researcher as 'camera man/woman' has been criticized by Banks (1995), on the grounds that the visual representations are produced by the investigator with the danger of the content taking priority over the context. Gauntlett (2005) also argued that this approach relies on interpretations of instant responses rather than more reflective self-expressions, and it fails to give participants the opportunity to express creatively, or to affect significantly the research agenda.

The professional videographer has been criticized by DuFon (2002), arguing that the s/he may have alternative agendas to those of the researcher who may want a more accurate story. Harper (1998) describes the researcher 'seeing the image-maker ('videographer') choosing points of view that illuminate different aspects of the unfolding social reality' (p.727). These concerns underpin ongoing debates regarding the ontological status of visual material generated through the camera. Can such data be regarded as a form of evidence or simply as the researchers' own perspectives? These debates lead to questions of the authority of visual data (see Dicks *et al.*, 2005). Although visual images record the world as it appears to the image maker these are not transparent or direct representations of the world or its objects (Ball & Smith, 2001). They display the world in particular ways. In other words, visual images portray 'specific points of view'. Most visual images are made, presented, looked at, and used by people. But that is not quite the same as looking at the question of subjects and self (Doy, 2005).

The third choice of image maker is the research participant. Worth & Adair (1972), early proponents of this approach, gave a camera to Navajo Indians to produce a film with no teaching or discussion of content, in order to see the world from the 'native's

point of view. In this way, they gained an understanding of Navajo cognitive patterns, narrative style, and ordering of time and space.

A number of studies have used various visual methodologies with children and young people, including self-representation approaches such as video diary or video tours to gain deeper understanding of a range of phenomena including childhood experiences of asthma (Rich & Chalfen, 1999), of the primary school classroom (Noyes, 2004), and of living in rural areas (Tucker & Matthews, 2001). As research with children has developed and participatory research methods have expanded, visual methods in child-centred or child-led research have proved to be particularly important for developing deeper understanding of children's perspectives and have the potential for extending understanding of children's worlds even further (Young & Barrett, 2001, Harrison 2002:862).

These methods have been termed 'indigenous ethnography' (e.g. Holliday, 2000), and I adopted this approach in my study, asking participants to make films about themselves and by themselves. Fundamental to this approach is the need to move away from the typical researcher/researched position. Children are the primary source of knowledge about their own views and experiences (Alderson, 2001:151). What I wanted for this study was a different voice, creating new ways of understanding the siblings of disabled children and their everyday worlds. This approach is important as the use of PMP by participants offers insights into the insider's view of the world - the emic perspective. This is particularly advantageous when children are involved in research that has previously relied on information garnered from parents or other adults (e.g. Gabhainn & Sixsmith, 2005, Goldman, 2004; Ross, 2005). The value of this approach lies in allowing children 'to construct accounts of their lives in their own terms' (Holloway & Valentine 2000a:8), avoiding adult assumptions about children's capabilities, facilitating research 'with children' rather than 'about children' and illuminating different experiences of childhood (Young & Barrett, 2001:144).

Although auto-ethnographic genres have been criticized for being self-indulgent, narcissistic, introspective, and individualized (Wall, 2006), indigenous approaches offer participants greater opportunities to represent themselves as they wish to be represented. The meanings are produced not through the researcher's understanding, but through

participants' own perspectives. Visual ethnography can be a very powerful methodology for showing a story of 'self'.

### 4.3.3. 'Points of Viewing'

Visual material provides a reality which is more accurate, detailed and complete than unaided observation (Lomax & Casey, 1998). I am aware, however, that visual ethnography does not produce objectivity or visual truths (Ball & Smith, 2001). *Selected reality* results from the positioning of the camera and the breadth of the lens, limiting the visual image to whatever is in its view. There will always be a gap between the visual image and reality because the image is always dependent on the image maker's point of view (Mason, 2005; Penn-Edwards, 2004). Therefore, Ball & Smith (2001:304-5) argue that 'photography or film do not unambiguously and transparently record reality' reflecting Denzin's (1997:284) claim that 'ethnography is interpretations, not just records of human experience'. In my study, therefore, I am not only interested in the visual images, but also in who makes them.

Traditionally, the ethnographer always explores two places: 'being there' and 'being here'. As Pearson (1993:ix) puts it: 'being an ethnographer is to be in two places at the same time' (cited in Roberts, 2001). Roberts (2001) explains that underpinning this assumption is an understanding that rests upon the added requirement of having 'been there' and observed, or even participated in, the social activity which constitutes the context of the research. Once returned from the field, the ethnographer must think about his/her research by 'being here', back in his/her own lived context.

In relation to visual ethnography, 'visual inquiry is no longer just the study of images, but rather the study of the seen and observable' (Emmison & Smith, 2000:ix). Pink (2001b) states:

An individual ethnographer does not have an single and fixed identity as a video maker, but this will be negotiated and redefined in different contexts. To be reflexive ethnographic video makers need to be aware of how the camera and video footage become an element of the play between themselves and informants,

and how these are interwoven into discourses and practices in the research context (p.80).

The meanings of visual images are not directly represented, but are constructed by image makers (the videographer) or viewers (Lutz & Collins, 1993, Becker, 1998, Pink 2001a, b). Then we should ask 'whose meaning?' Bogdan & Taylor (1975:11) argue that 'different people may interpret the same things differently, just as the same person may interpret things differently at different times'. Kellett (2005a:44) also argues that an 'outside looking in' style of observation is inevitably affected by observers' subjective judgements, even low levels of filtering of what they are seeing. Seeing is the result of an active and learned process of looking (Berger, 1972:8). And it is not possible to understand totally children's worlds through adults' points of viewing (Eder & Corsaro, 1999). Adult ethnographers are limited by their tendency to process children's lives through their own points of viewing. Therefore, ethnographic research with children requires that the researcher moves away from adult-centred understanding of a phenomena and seeks to understand the ways in which children's social worlds are shaped and controlled by them (Emond, 2005:124).

In line with the '*Archimedean Perspective*', that refers to changing knowledge in accordance with one's own perspective, I adopted Goldman-Segall's (1998) notion of '*point of viewing*'. Goldman-Segall (1998:4) explains that the notion of point of viewing broadens our scope, to understand various ways of seeing and interpreting, and to emphasize how we construct and combine knowledge. The notion recognizes that different people inhabit different worlds which constitute for them diverse ways of knowing, distinguishable sets of meaning and separate realities (Crotty, 1998:64). Instead of knowledge being fixed, it is conceived of as multiple, fragmentary, and context-dependent (Hare-Mustin, 1994:20). Knowledge arises from the interaction of an observer with their social, cultural, historical, economic and political environment. This epistemological stance contrasts with the positivist approach that assumes objective observations of the world can be made from neutral positions. The values and interests of the observer are always operative depending on what is being observed. Children, therefore, produce knowledge based on their own points of viewing. To elicit understanding of children's points of viewing, they must be given opportunities to



depict their own stories in their own languages. Kellett (2005a) argues that this is the best way of understanding the lives and experiences of children in socio-cultural context. Encouraging children to see themselves and their own worlds can also break the stereotypes that result from adults' points of viewing and can serve to inhibit understanding of children as active agents.

I do not claim that children's voices are the best, but hearing and seeing the everyday lives of children through their own points of viewing offers a better understanding than merely listening to the ethnographer's story. Visual ethnography has greater potential to convey children's everyday lives than text alone. Pink (2001b:13) argues that 'by paying attention to images in ethnographic research and representation, it is possible that new ways of understanding individuals, cultures and research materials may emerge'. I argue that videography is able to broaden the scope of imagery to provide more detailed contexts behind the text more than is possible with photography. I do not claim that visual ethnography is the best tool for enabling children to express their own stories, but it does offer a medium for exploring the actual experiences of participants through their own points of viewing.

## **4.4. Researching with Children**

### ***4.4.1. Children as Active Researchers***

Childhood has been constructed through socio-historical assumptions and beliefs (Harden *et al.*, 2000, Prout & James, 1997). These include seeing the child as object, subject, and social actor (Christensen & Prout, 2000, Hendrick, 2000). The traditional, and still very common approach is to see a child as an object (Kellett *et al.*, 2004, Christensen & Prout, 2002). Christensen & Prout (2002:480) argued that this approach neglects an understanding of children as social persons in their own right. Children are implicitly identified as incompetent with limited understanding of research, lacking ability to consent or have a voice in its design, implementation and interpretation. This perspective is associated with investigation of childhood from adults' perspectives through the accounts of parents or other adults who have responsibility for children.

The traditional perspective has been challenged by the '*child-centred*' perspective that recognizes the child as a person with subjectivity and is associated with developmental psychology (see Woodhead & Faulkner, 2000). But the validity and reliability of the child centred perspective has been challenged on the basis of age and competence and researchers have been cautioned to pay attention to children's stages of development and maturity (Kellett, 2005b). Christensen & Prout (2002) and Alderson (2000), however, reject this critique since adopting particular criteria for children of particular ages reinforces the use of a narrow range of data collection tools and blocks the empowerment of 'children as active researchers' (Kellett *et al.*, 2004:330).

Adopting a children's rights perspective, children are seen as social actors with their own experiences and understandings (Hendrick, 2000). Here, children are seen as autonomous beings (Corsaro, 1997; Thorne, 1993) rather than simply as part of a family or school (Alderson 2000; Christensen & Prout, 2002; Cosaro, 1997). James (1995, cited in O'Kane, 2000:139) refers to the 'social child' as being similar to an adult but with different social competences. And research engaging with children depends upon moving beyond children as the objects of research (Kellett *et al.*, 2004; Barker & Weller, 2003:208). A children's rights approach encourages the use of research methodologies that engage effectively with children, encouraging children to participate by communicating their own knowledges and enabling researchers to learn more about their experiences of the world.

Since a children's rights perspective argues that children's social relations and culture are worthy of research in their own right, Alderson (2000:244) poses the question: who is better qualified to research children's lives than children themselves? The dilemma is that adult researchers may not be able to recognize children's worlds because they cannot be full participants in children's social worlds and cannot be children again (Hill, 1997). Punch (2002b:322) argues that adults researching children poses problems associated with a power imbalance between researchers and children, but these problems are not always adequately addressed.

The practice of involving children as active researchers has been understood in terms of developing a new social science methodology (Hill, 1997; Alderson, 2000, 2001;

Woodhead & Faulkner, 2000; Kellett *et al.*, 2004; Kellett, 2005a). Based on children's rights (UNCRC), the desire to increase children's involvement in decision-making affecting their lives has led to growing support for children's participation. Alderson (2000) and Grover (2004:91) argue that 'allowing children to be active participants in the research process enhances their status as individuals with inherent rights to participation in society more generally and the right to be heard in their authentic voice'. This approach treats children as co-producers of knowledge (Alderson, 2000; James *et al.*, 1998). Despite the challenges in conceptualizing children's participation in research (see Beers, 2002; MacNaughton *et al.*, 2007), many studies have reported children's participation from principles, practices, policy and epistemological stances (Lansdown, 1995; Hart, 1997a, b; Flekkøy & Kaufman, 1997; Johnson *et al.*, 1998; Prout 2000; Sinclair, 2004), in which the issues of power, voice and representation have been central to debate of children's participation (see Kellett *et al.*, 2004). These debates have influenced the choice of methods, including the researcher's role in data collection, the analysis and interpretation of data (Veale, 2005).

Although children's active participation has been critically debated (see above), it is argued that it is children's right to participate in research, a right that should be honoured by adult researchers. James (2001) claimed that:

It is the use of ethnography as a research methodology that has enabled children to be recognized as people who can be studied in their own right ... and made possible a view of children as competent interpreters of their social worlds ... and has steered researchers to doing work with rather than on children (p.246).

My study adopts an approach of children as 'active researchers' presenting and interpreting their own knowledge, meaning, values, and experiences. The children as active researchers can be involved in the research process in different ways (Alderson, 2000). In my study children are involved in i) collecting data by themselves, ii) determining the content of the data, and iii) analysing and interpreting the data that consists of their observations, experiences and reflections as well as how they negotiate and construct reality through interactions with parents, older or younger siblings and other children. I did, however, influence the frameworks for visual data collection by

asking the children to record their lives over two weeks using video diaries and making home movies (see section 4.6.3).

#### **4.4.2. Children's Position**

The imbalances of power and status between adult researchers and children have been strongly challenged (Mayall, 2000; Punch, 2002b). In my study children are active researchers in their own right, used their own abilities and capacities, and were their own videographers. This moves beyond the traditional positions of adult researcher and researched children. My study reduced the adult researcher's control and power over the research process by encouraging children's full participation, allowing the children control over the data collection, and opportunities to explain and interpret the data. Kellett *et al.* (2004) make the important argument that:

The adult ethnographer cannot entirely bridge the divide and 'become a child again' however invisible she or he attempts to be in the immersion process. .... This is not to devalue the research carried out by adult ethnographers.... Rather to propose going a step beyond involving children as participants to handing over the initiative and empowering them as active researchers (p.331)

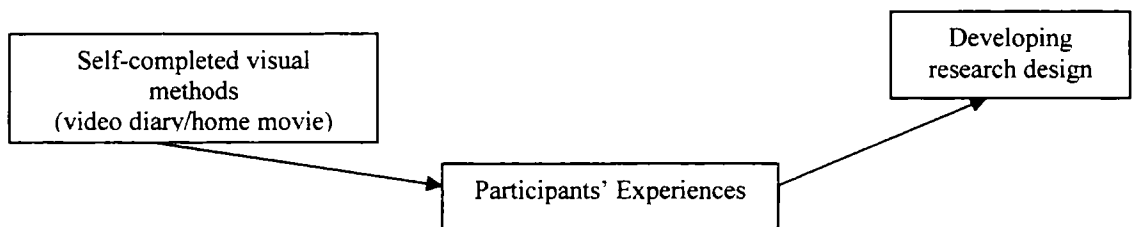
It would not have been possible for me to capture the reality of day-to-day life for siblings without living with the family for an extended period, and even then I would have been a stranger, or outsider, having little in common with the participants. My role was in supporting children as 'invisible ethnographer', sharing power in the research context to enrich the interaction between researcher and children. Although the processes of data collection and interpretation were controlled directly by children, they needed support in understanding how to use the video camera, and I used phone contact both to remind them of their plans for filming and to listen to them, something they valued highly. In this way we developed closer relationships, akin to friendships, that helped to promote collaboration between us, and went some way to redress the traditional adult/child balance of power (Johnson, 2004). Pink (2001b) writes about collaborative approaches in visual methods that seek to reduce the distance between researcher and participants through empowerment (see Kindon, 2003). Collaborative

approaches break down hierarchical relationships between researcher and participants. They are also useful in attempting to understand and represent participants' points of view and experiences that are not easily observed, and in recognizing how experiences have different meanings for different people.

## 4.5. Pilot Study

In order to test the feasibility of the technical aspects of data collection and analysis, and to gain experience of working with children in this way I undertook a pilot study in the North East of England with the brother and sister of an autistic adolescent. The basic design for the pilot study is set out in Figure 4-1:

**Figure 4-1** Pilot Study Design



This pilot study was valuable for:

- testing the feasibility of self-completed visual methods, both in a technical sense, but also in the sense of learning and reflecting on my own skills in engaging with different members of the family that were vital to motivating and sustaining the siblings in the process of data collection and engaging in data analysis and interpretation,
- checking time and budgets to work with children in the main study,
- considering the practical and technical challenges and difficulties, including children's unsupervised use of the PMP,
- preparing research guidelines for children and their families,
- developing research questions, and

- developing qualitative analysis techniques.

#### ***4.5.1. Participants of the Pilot Study***

Participants for the pilot study were recruited through a Young Carers' Project. Using a voluntary and criteria sampling approach (aged 7-15, living with both parents and an autistic sibling) I was able to recruit family P consisting of:

- FP father, employed full time
- MP mother, not employed
- DP 17 year old autistic adolescent, older brother to:
- RP 15 year old brother
- JP 10 year old sister

DP was obsessed with DVDs popular among teenage girls. He had unpredictable episodes of aggressive behaviour during which he would break household fixtures and fittings. He watched his DVDs at loud volume in a second family room. He attended a 'special school' and was due to go to a residential college at the end of the school year.

RP and JP spoke with strong North East accents. RP appeared to experience tensions with his parents over DP's disruptive influence on family life. JP was especially disrupted by DP. For example, DP often broke her room door and took her belongings (e.g. DVD, accessories) and she had to hide her belongings from DP. Both RP and JP were involved with a Young Carers Support Group.

#### ***4.5.2. Running the Pilot Study***

The field work for the pilot study was conducted in March 2005. Following an unsuccessful attempt to identify a family with an autistic child through the newsletter of the National Autistic Society a direct approach was made to a local Carers' organization that ran a support group for young carers. One of the workers was FP, father to an autistic son and two normally developing younger children, and he agreed to discuss the possibility of undertaking the pilot exercise with his family. The information leaflet

with consent forms was used. It took two months to obtain agreement from the family members; the result of a child-centred approach by FP and MP who were concerned that RP and JP should fully understand what they were agreeing to and give their consent freely.

For the first meeting, I visited the home with one of my academic supervisors who was practiced in the use of visual methods. We discussed the family's involvement in the research with further details of what the pilot study involved. I explained to the children that I was interested to know their experiences of daily family life. I explained how they could use daily video diaries to give a day by day picture of their experiences, thoughts and feelings individually, and use the home movie to show whatever they wished to show of daily family life. Written consent was given by both parents, RP and JP. DP's father explained that RP and JP were planning to take a video in their home and asked if DP was happy to be included in the home movie. DP responded positively and his father felt confident that DP had understood and had indicated his willingness to be involved. Guidelines and information about technical supports for making a home movie and video diaries were given (see Walsh *et al.*, 2007). RP and JP were asked and arrangements made for a second meeting. In this meeting, the family expressed concern about the ethical problems arising from visual methods. Ethical issues are discussed fully in section 4.7, but it is important to indicate here that this experience in the pilot study served to remind me that reassurances about privacy and confidentiality must be reinforced beyond simple inclusion in the consent form. The parents wished to be reassured about arrangements to protect family identity and confidential treatment of the data. I repeated my commitment to protecting the identity of the children and the family and confidentiality of visual images by ensuring that:

- the films would be safely stored with a protective code on my computer. Video data were to be seen only by me and my academic supervisors and no printed images of video data would be produced;
- any transcribed materials from the video diaries, home movies and additional interviews would be stored in a locked filing cabinet in the researcher's room to which only the researcher had access;

- any description of family members who took part in the pilot study, as part of writing up whole thesis, would disguise details of individuals, the family and place in order to guarantee anonymity.

With these reassurances, the family agreed to proceed and were actively interested in the project. The PMP (Archos AV380) designed to capture everyday life was left with the children for one week. A second meeting followed the first week of filming. The children had made a few video diaries, but had not attempted a home movie. I made a copy of the video diaries and left the PMP with the children to make more video diaries and one or more home movies. RP and JP made audio-diaries in the second week and at our next meeting I explained that they had misunderstood what they should do with PMP. I explained and showed them again how to use the equipment and they readily agreed to give the process another go for a further week. This experience reinforced the need for me to be very thorough in providing guidelines and checking children's understanding about the task and the use of technical equipment.

At the end of the following week, in which both children made further video diaries and RP had made a home movie, I held reviewing sessions with each sibling individually in their home. They were asked to explain and interpret their videos including what happened, clarifying meanings and context. Interviews with both parents together took place in the home a week later. Drawing on the data from the video diaries and home movie, but without revealing the content directly, I asked FP and MP to talk about their perspective of the everyday lives of JP and RP.

I made five visits to the family in total and at each stage I reconfirmed consent. I also made contact by phone to check progress, offer support and resolve any unexpected difficulties. At the end of the process RP and JP were given vouchers in acknowledgment of the time they had spent contributing to the study.

#### ***4.5.3. The Pilot Study Experiences***

After the pilot study, I was able to make crucial changes to some of the procedures, methods and instruments, in preparation for the field research.



#### 4.5.3.1. Rethinking Camera Power

RP and JP made their own decisions about how and when to undertake the video in their home without direct intervention of the researcher and this was very fruitful in accessing the children's own views and thoughts. Their enthusiastic participation was based on excitement about making videos by themselves. The PMP was an attractive data collection tool that avoided the 'invisible wall'<sup>18</sup> created when children are conscious of the presence of the adult researcher. Gauntlett (2005:17), found that an open research strategy allowing children to express themselves led to a much more rounded picture of children's experiences than the use of adult led data collection. And the use of video, in particular, enables greater freedom of expression (Holliday, 2000:511), as children turn from 'passive viewers' to 'active producers', empowered to engage in research. JP and RP enjoyed the opportunity for freedom and choices in what they expressed without adult intervention. The pilot study confirmed that these self-generated visual methods offer a largely unobtrusive route to understanding the realities of children's daily lives.

The pilot study confirmed a high level of new technological knowledge among children. RP and JP learned the functions of the PMP very quickly, including functions that were not central to the data collection for the pilot study. Noyes (2004) has demonstrated that children are deeply familiar with multimedia and enjoy using video cameras. In producing 18 video diaries, 2 home movies, 10 audio-diaries of daily scenes at home, RP and JP never expressed boredom or dislike of the process, and their recordings provided key insights into their lives that I could never have observed directly.

An important lesson from the pilot study was that filming within the home may be disrupted by the autistic child (Higgins *et al.*, 2005; Bromley *et al.*, 2004) or fear of disruption. The video diaries of RP and JP both refer to their autistic brother 'kicking off', and one of the home movies included the words of one parent reminding RP not to go too close to his brother with the camera for fear that he might 'kick off'. If children are to film whatever they wish to portray about their daily lives, and if this includes

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<sup>18</sup> The main difficulty of ethnography with children that relies on participation observation is that the adult researcher can never be a child again and cannot easily understand children's social worlds.

their autistic sibling, then we must accept the additional challenges that arise and give careful consideration to the potential for harmful situations arising from autistic siblings' physical disruption and unpredictable behaviours. For the main research study, therefore, I asked parents to keep a watchful eye on the autistic child while the sibling was filming.

The challenges of the visual method were that: i) video data conveyed very complicated and complex information, including actions, interpersonal dynamics with associated tensions and sensitivities, ii) much of the context behind the PMP remained unexplained, and iii) I could not control the quality of data. For these reasons, the diaries and movies were discussed with the siblings in a process of '*video elicitation*'<sup>19</sup> (Banks, 2007:72). In the pilot study, the reviewing sessions with the participants offered richer understanding of the content within the video data. But the timing of reviewing sessions must be carefully considered as participants may forget the significance of particular actions, words or expressions. In the pilot study, the reviewing session took place one month after making the first video. The children could not remember the significance of all their words or, where they took a video, the events they had filmed. This lesson led to the re-design of the research schedule for the main study to ensure that all work with each family should be completed within a period of three weeks.

Another challenge of using visual methods was that the quality and quantity of data depended on children's experiences, and choices. I could not control the children's choices about what and how much to film as they were asked to take a video of whatever they wanted. RP and JP did not have experience of making videos, and I had hoped that they would make more than two home movies. I was also surprised when they made audio diaries during the second week. These lessons from the pilot study led me to arrange one-to-one workshop sessions in the main research, so that children could develop their skills, be clear about the purpose of the research and be mindful of the research schedule.

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<sup>19</sup> This term was originally called 'film elicitation'. This technique (as photo-elicitation) is used in many kinds of social research. Banks (2007:72) suggested that this technique should be used to elicit data from internal (the story was told to the viewer) and external narratives (here-and-now context of [interview], and there-and-then context of image's original production) of the image.

Lastly, using the PMP brought technical challenges (e.g. slow starting time and slow shutter speed, no tripod fixture, dark screen and short battery lifetime). Identifying these problems in the pilot study led to a change of equipment for the main study (mini DV type camcorder and upgraded version of the PMP (Sorell AV-15)).

#### ***4.5.3.2. The Impact of the Camera***

RP and JP reacted quite differently to the camera. JP, the ten year old sister, took only video diaries providing information about aspects of her personal daily life. RP, the 15 year old brother, used the video diaries to express how his life was affected by his autistic older brother. DP, their older autistic brother, disliked being filmed. And during RP's making of home movies, the family become 'camera conscious' creating styled performances in which they said 'hi there' towards the camera, but little else. Clearly it was difficult to videotape in the natural state and this experience led me to provide some basic training to parents or other family members in the main study to enhance competence and encourage participation in the natural context.

Cultural and language differences needed careful consideration. Being an adult man from South Korea I was a total 'stranger' to this English family and vice versa. Although the videos showed routines of ordinary daily life, I could not understand perfectly the experiences and normative expectations from the perspective of the children's own culture. A particular challenge lay in understanding the children's expressed English that had an accent unfamiliar to me, and included words particular to the local cultural context. To overcome this challenge the parents assisted me in gaining a broader contextual understanding, and one of my academic supervisors assisted in the transcription of the video tapes.

Although the main study was conducted within my own socio-cultural context, it was important to transfer learning from the pilot study and pay careful attention to communication style. In Korean culture communication styles are indirect and non-confrontational and demand different interview skills with Korean children (see Gudykunst *et al.*, 1996; Holtgraves, 1997). Therefore, I used art-based interview techniques to engage the children (e.g. drawings, spider-web, puppet) in the main study.

As Punch (2002a) has suggested, a combination of methods can enable the data-generation process to be fun and interesting for children as well as effective in generating useful and relevant data.

Using the camera in the home context brought particular ethical challenges. The parents concerns about privacy and confidentiality were addressed on several occasions in order to ensure that they felt confident with the arrangements for protecting their identity and maintaining confidentiality of the data (see details on pages 104-105). For the main study, in Korea, use of visual methods presented even greater challenges arising from a reluctance to permit insights into what is commonly considered to be a 'shameful' family situation, i.e. involving a disabled member. It was therefore necessary to anticipate additional time for negotiating access and preparing the ground for visual ethnography in the main study.

#### ***4.5.3.3. Handling Visual Data***

A further challenge of using camera techniques is how to interpret the data that are generated.

First, video elicitation was used for clarification and to gain a more accurate understanding of the data. This process, in which I discussed the visual images and accompanying words with the children, succeeded in offering additional information to allow more accurate interpretation. The only challenge lay in the reviewing session with JP. This gave rise to a dilemma in that as an older male researcher, I wanted to ensure that JP was comfortable to talk to me, and therefore asked her mother to be in an adjoining room with the door slightly open, but with enough distance to allow JP to speak freely with me. I anticipated the need to make these arrangements and the reviewing session went smoothly.

Second, I interviewed parents about the data collected by the children (but without revealing the visual representations) in order to place the children's data in the broader context of family life. This was very helpful in providing the wider contextual picture

that I was seeking, and did not raise any difficulties in terms of maintaining confidentiality of the children's accounts.

Third, I transcribed the video and audio diaries, the reviewing sessions and the words of the home movies using transcript conventions (see Sack *et al.*, 1974: 731-734; Atkinson & Heritage, 1984:ix-xvi; Jefferson, 2004:24-31). However, I learned that *Nvivo* (version 2.0) does not allow the researcher to link the transcription to the video footage. *Nvivo*'s hyperlink facility did not in fact allow me to link visual images with written transcript. The following extract from the transcript<sup>20</sup> of RP's home movie demonstrates the problem:

**RP:** It's dad (2s) over there (2s) ((MP and JP sit down on the couch)) JP and mum  
say hello  
[[<<lol(FP goes)>>  
**MP, JP:** hi  
**MP:** there (2s)  
<<FP moves, DP is standing at the kitchen door>>  
**RP:** hi DA ^@ lol(go to DP closely)  
**FP:** [[ say DP  
<<suddenly DP recognizes the camera>>  
**DP:** NO---  
\_@ lol(move back)  
**FP:** Don't gonna be face RP  
**RP:** I'm gonna be (2s)  
<<MP and JP are seeing>>  
^@ excuse lol(goes into the kitchen) (4s) \* >@  
°don't be gonna be there° \* \* <@ (2s) kicks off. It's kitchen \* he is bad mood now  
some ... don't know go back in there, just getting happens some .

This transcript is very complex and difficult to understand. There are also multiple dimensions to a transcript, some of which I have tried to capture using transcript convention codes. Denzin (1997) pointed out that 'a written text becomes a montage, a meeting place where original voices (or images), their inscriptions, and the writer's interpretations come together' (p.41). But written text may not fully deliver original

<sup>20</sup> I introduced a lot of new symbols which I need to explain.

(2s): time pause-2seconds, (( )) background [[ overlapping speech lol: cameraman action, << >> filmed actions ^@ camera gaze direction-up \* \* unclear speech, ° ° cameramen's comments

meanings of voice or image. Despite this difficulty, visual images continue to be commonly presented and understood as textual constructions (Denzin, 1997:32). Heath & Hindmarsh (2002) argue that transcription cannot replace the video recording as data, but provides a resource through which the researcher can begin to become more familiar with details of the participants' conduct. The experience of the pilot study, and the added insights from the methodological literature, informed my decision that for the main study, I transcribed only the words from the video data and linked these to video fragments using *Transana* ([www.transana.org](http://www.transana.org)), a software package in development (Spiers, 2004) that permits the simultaneous display of linked visual, audio, and textual material on one screen.

#### ***4.5.3.4. Developing Research Questions***

It is important to remember that the pilot study was based on white, Western, younger siblings' perspectives of daily life. The pilot study provided a conceptual profile of the experiences of the siblings that focused overwhelmingly on the negative.

But the Korean setting of the main study provided a different socio-cultural system with different meanings of siblinghood. Accordingly, I developed the original research questions to move beyond the simple understanding of the everyday experiences of siblings of autistic children to encompass a broader understanding of how siblings are identified in Korean socio-cultural systems, and how this shapes (a) sibling's self-identities and roles and (b) their understandings of relationships with their autistic siblings, (c) daily life within the family (d) daily life in wider society (d) hidden vulnerabilities.

## **4.6. Field Research Setting and Data**

The main study was carried out in two cities in Korea where I had existing social networks that would facilitate access to families with autistic children.

### **4.6.1. Participants**

#### **4.6.1.1. Snowball Sampling**

Families with disabled children in Korea represent a 'hard to reach' group, largely because of the shame associated with disability. The most common sampling method for such groups is snowball sampling (e.g. Faugier & Sargeant, 1997; Petersen & Valdez, 2005; Magnania *et al.*, 2005), and this was the approach used in this study. There are different ways of accessing potential participants (Bryman, 2001; Arber, 2001) and in my study, I employed two approaches. The first was to identify a key informant in the study population, with the hope that s/he would recruit a second participant who in turn would provide a third participant and so on (e.g. McKnight *et al.*, 2006). Although this approach succeeded in identifying adults (with whom I had worked professionally in the past) who gave me permission to invite their children to participate, it failed in terms of recruiting child participants.

My second method was to use social networks, and I made contact with parent support groups. One parent introduced my study to other parents who expressed interest (Spren & Zwaagstra, 1994; Browne, 2005). Employing social networks was very useful in accessing and recruiting potential participants. It gave opportunities to participants to discuss my study with other potential participants. In this way they were able to '*check out*' both my research and me (Browne, 2005:50). One advantage of the snowball sampling strategy lay in the assumption that insiders may know who are the most knowledgeable within the social network (Salganik & Heckathorn, 2004). The second advantage was in developing trust in me and my study because it was introduced by the participants in similar circumstances, rather than by an agency or other researcher. Indeed, Atkinson & Flint (2001) have commented that trust can be developed as referrals are made to participants with similar circumstances rather than other more formal methods of identification.

However, snowball sampling strategies carry inherent problems of representativeness and generalizability (Bryman, 2001; Heckathorn, 2002). Browne (2005:51) also argued that 'findings from a small number of participants can amount to 'Tokenism', running

the risk of reinscribing particular categories of difference and making assumptions of homogeneity within predefined categories'. These critical arguments are beyond the scope of this thesis. But I argue that while the sample size in this study is small, it did reflect the urban socio-cultural environments and consequences of having autistic siblings in Korea. Furthermore, evidence of the homogeneity and persistence of Confucian familist values in contemporary Korean society (Yang & Rosenblatt, 2008) suggest it is likely that the experiences of children with autistic siblings in other urban areas of Korea will be similar.

#### ***4.6.1.2. Sampling Procedure***

A snowball sampling strategy was used to identify families with an autistic child and at least one sibling aged 7-15. However, I had to repeat the strategy starting with a second source in order to achieve a reasonable sample. First I approached two parent support groups (reaching approximately 74 families) in Incheon to see if any families would be willing to participate in the study. The advantage of contacting parent groups was that I had worked as the director in a special education centre and Sunday school for disabled children for 9 years. The current director of the centre agreed to distribute the research information package, written in Korean, to the parent support groups (See Appendix-A). Each parent was asked to inform other families with autistic children, known to them, about the study.

A number of factors limited willingness to participate in the study. Some families, affected by the shame associated with disability, were not comfortable or willing to focus attention on this aspect of their family life. Even where parents were willing, some siblings were not willing to participate. One boy withdrew after initial contact because he was concerned about revealing the hardship of the family, although his mother was willing to participate. The well documented limitation of snowball sampling, its reliance on individuals' willingness to be involved, was strongly evident in my study. Of an original sample of 11 families, four chose to withdraw after initial contact, and in two cases during the research due to a parent's illness and serious injury, reducing the sample to 7 families. To achieve a larger sample, I contacted a Presbyterian church in Seoul that was closely involved with a special education school for disabled children.



The minister distributed the research information package to parent support groups and two further families agreed to participate to achieve a sample of 9 families.

The final sample of siblings of autistic children, on whom the study focuses, is described in Table 4-2. It included 5 sisters and 4 brothers aged between 7 and 15, offering a range of developmental stages, all judged able and competent to engage with the technical aspects of data collection and talk about their lives, their autistic siblings, families and wider society. Pre-school siblings were excluded from the sample on these grounds, while siblings over 15 were excluded on the grounds that this age is associated with intense study as they prepare for university entrance exams.

It was not possible to set any criteria relating to the diagnosis of autism since there is no common system of diagnosis in Korea and it is not possible to access medical records.

Table 4-2 Characteristics of the Participants<sup>21</sup>

Case	No of child <sup>22</sup>	Siblings				Autistic Children				Living area	Parents' Occupations <sup>23</sup>	Religion
		ID	age	gender	education	ID	age	gender	education			
1	2	A1	15	Girl	High school	A2	17	Boy	Special high school	Inchon	1. Shop owner 2. part time classroom assistant	Christianity
2	2	B1	7	Girl	Private day kindergarten	B2	9	Boy	Special elementary school	Inchon	Technician	Christianity
3	3 <sup>24</sup>	C1	13	Boy	Elementary school	C2	18	Boy	Special education class in High school	Inchon	1. Teacher 2. Part time teacher	Christianity
4	2	D1	8	Girl	Elementary school	D2	6	Boy	Integrated kindergarten	Inchon	Professional	N/A
5	2	E1	12	Boy	Elementary school	E2	10	Boy	Special education class in elementary school	Inchon	Banker	Christianity
6	2	F1	8	Girl	Elementary school	F2	9	Girl	Elementary school	Inchon	Small Business (Transport) owner	Christianity
7	2	G1	12	Boy	Elementary school	G2	8	Boy	Special education centre/therapy centre	Inchon	Shop owner	Christianity
8	2	H1	13	Girl	Middle school	H2	11	Boy	Special education class in elementary school	Seoul	1. Practice vicar 2. Part time classroom assistant	Christianity
9	2	J1	13	Boy	Middle school	J2	10	Boy	Special elementary school	Seoul	Civil servant	Christianity

<sup>21</sup> In this study, only one autistic girl was included, reflecting the prevalence of autism in boys and girls. Although it is difficult to explain, this comparative prevalence is common worldwide (Ehlers & Gillberg, 1993; Kadejō *et al.*, 1999) and in Korea (Lee, S.H., 2002).

<sup>22</sup> Total number of children in family

<sup>23</sup> This study focuses on a middle class sample and this places some limits on the generalizability of the findings to other socioeconomic groups. In terms of income, National Statistics ([www.kosis.kr](http://www.kosis.kr)) indicate that the income of single income families (e.g. cases 8 (low income occupation) and 5 (high income occupation) ranges from 2,893,850 to 4,835,417 Korean won (national single income family income 3,068,875 Korean won in 2006). Cases 1, 3 and 8 were dual incomes

<sup>24</sup> In this case, the oldest sister (C3, aged 20) was excluded

#### 4.6.2. *Field Research Procedure*

The study was carried out between August and December 2006 (see Appendix-B). The first stage involved meetings with the siblings and their parents to provide details of what would be involved, to confirm agreement to participate, and arrange a further meeting at a time and place nominated by the participants.

Before embarking on diary recordings and making home movies, all sibling participants were trained in the use of the PMP or camcorder with the purpose of developing their '*camera vision*' (Chiarenza & Luxenberg, 2004) - a heightened awareness of framing and capturing scenes. They all learned the technical functions of the PMP and camcorder easily: how to record, check the video, and recharge the batteries. The PMP was more user-friendly and more easily operated, but all the siblings felt comfortable with both tools. Punch (2002b) pointed out that:

The issue of using appropriate methods is a central concern in any research but with children there seems to be a greater desire to develop fun, 'child-friendly' methods, drawing on familiar sources or children's particular interests (p.329)

The siblings were free to record, edit and delete footage as they wished. They were, however, given basic training in how to frame the images they intended to convey. The parents of the three youngest children (7 and 8 years old) were also trained so that they could lend support **if requested by their children**. The training sessions proved useful in developing competence. For example, one sibling using the camcorder started by filming the desk rather than his face (while practising recording the video diary) and was unaware of how to swivel the screen.

The siblings and their parents were provided with technical guidelines for the use of the video recorders and the siblings were asked to make a daily record of whatever they considered to be important in their lives. Similarly, the only guidance for the home movies was that they should record anything the participants' wished to film that reflected family life. Timing, place and content were chosen by the participants, though they were aware of the purpose of the study and this may have influenced the content of the video diaries and home movies. The guidelines were designed to maximize the amount of 'useful' visual data collected, but aimed to maintain the free-form approach

for filming whatever the children decided to capture, allowing them free expression (Deacon, 2000).

After the training sessions with each family, the siblings kept the PMP or camcorder for two weeks. They recorded episodes at home or out of home throughout the day to reveal significant aspects of their everyday lives. In the video diaries, participants spoke directly to the screen offering '*personal monologues*' (Rich & Chaflen, 1999:56) that conveyed their own experiences, observations, thoughts, and feelings. The video diaries formed the basis for a reflective process in which the siblings reported, and expressed their thoughts about, significant events in their daily lives.

At the end of the two week period, I collected the camera, watched and annotated the recordings before returning to hold reviewing sessions with the siblings in their own homes. Reviewing sessions with siblings were carried out in privacy, but a parent was always present elsewhere in the house. Parents<sup>25</sup> chose to be interviewed at the autistic child's school or special education centre. This allowed them to concentrate on the interview that focussed on their perspectives of the lives and experiences of their non-disabled children, permitting me a deeper understanding of each child's family context (Appendix-C).

At the end of the research process each sibling received vouchers or presents to the value of £20 in recognition of their time and contribution to the study. This research process is summarized in Table 4-3:

**Table 4-3** Field Research Process

Stage	Home visit	Time frame	Activity
Preliminary	Initial visit		Recruit participants, distribute research information, gain informed consent (sibling and parent)
Phase 1	First visit	Day 1	Check participation, explain research process, confirm consent, distribute PMP and provide technical training
	Between visits	Days 1 – 14	Children take home movie and video diary Researcher checks progress through telephone contact
	Second visit	Day 15	PMP collected from children
	Between visits	Days 16-23	Recordings viewed and annotated
	Third visit	Day 24	Reviewing session with sibling
Phase 2	Final visit	Day 31	Interview with parents to gain their perspective on the lives and experiences of their normally developing child [sibling].

<sup>25</sup> In 7 cases parental interviews were with mothers only. In 2 cases (A1, H1) interviews were held with mother and father together.

### **4.6.3. Data Collection Methods**

Visual data were generated by the siblings of autistic children using visual ethnographic methods to investigate the daily life of siblings. This is a relatively new development and contrasts with the majority of studies about children and childhood that have been framed from adult perspectives. This study is underpinned by values of child centredness, however, it is also important to note that it would not have been possible for me, as an outsider to the family, to gain insights into daily family life in a socio-cultural context that is characterized by shame and stigma associated with disability (see section 3.2.)

Instead of traditional methods, therefore, my study uses methods that are participative, nondirective and creative, where ownership and control of data collection lies with the children rather than a professional filmmaker or adult researcher. Using this methodological strategy, children's views and experiences of daily life were explored through the lenses of PMP (Archos AV380, Sorell SV-15) for 7 children and mini DV type camcorder (Panasonic PV-DV101D) for two adolescents (Case 8, and 9)<sup>26</sup>.

#### **4.6.3.1. The Video Diary**

The use of diaries has been documented (see Alaszewski, 2006), and is suited to a naturalistic approach being designed "to examine ongoing experiences, offer the opportunity to investigate social, psychological, and physiological process within everyday situations" (Bolger *et al.*, 2003:580). Diaries offer powerful forms of capturing taken-for-granted activities including daily stressors (Almeida, 2005), marital and family processes (Laurenceau & Bolger, 2005), housework participation (Kan, 2006), and time management (Innis & Shaw, 1997). Johnson & Bytheway (2001) concluded that the use of the diary method can offer insight into other aspects of daily lives. Moreover, diaries can be used to provide greater insight into how participants interpret situations and ascribe meanings to action (Alaszewski, 2006:37).

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<sup>26</sup> The main reason for the use of the camcorder was that the PMP (Archos AV35) was broken and temporarily unavailable.

In contrast to written and audio forms of diary, video diaries offer powerful self-portraits of everyday lives and more detailed accounts of the meanings. For example, Barnes *et al.* (1997:27) argued that video as an empowering visual medium, offered women, ethnic minorities, HIV+ people, and other marginalized groups the opportunity to reproduce and understand their own worlds as opposed to the dominant representations depicted in the mass media. Pini (2001) points out that the video diarist can feel less scrutinized since there is no observer. Noyes (2004:10) argued that the video diary offers researchers a different means of exploring social experience. And Holliday (2000) concluded that “video diaries do appear to offer a glimpse into the everyday worlds of respondents in unique ways.” (p.515). In my study the video diary represents a means of recording children’s points of view, a means of enabling participants to recreate (reinterpret) their environment (Noyes, 2004), and a means of empowerment in ‘making visible’ marginalized or invisible groups (Pink, 2001a).

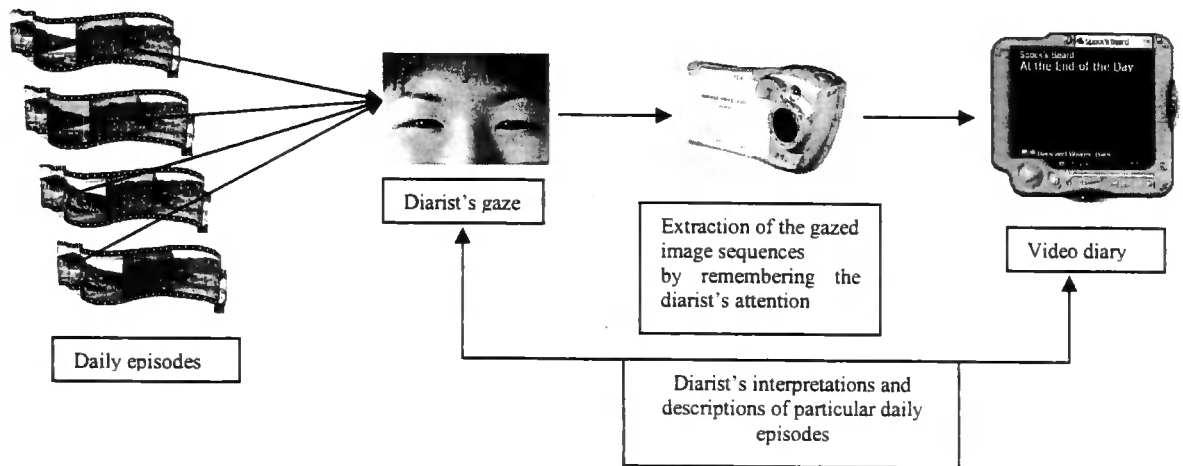
The Korean children in this study were already familiar with the concept of video diary, which is common in TV reality programmes. The availability and familiarity of digital video-recording technology made it feasible to ask siblings to tell stories from ordinary daily life without the presence of the researcher. The children were asked to videotape when they were alone, speaking directly to the PMP about their experiences, observations, and feelings of that particular day.

Using words, and displaying facial and bodily expressions, the children offered accounts of their chosen episodes of daily life (see Figure 4-2). I do not claim that the video diaries present a unified truth of selfhood, but I argue that the self-directed video diary approach offers a new way of conceptualizing the process of ‘othering’<sup>27</sup> and reinterpreting the ordinariness of everyday life.

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<sup>27</sup> There has been concern that disabled people are perceived as ‘other’ or ‘different’ resulting from dissimilarity from the perceived norm (see Clapton & Fitzgerald, 1997). However, perceptions of otherness, and ascribed meanings of the experiences of othering can be shaped differently by broader aspects of culture (Murdick *et al.*, 2004).

Figure 4-2 Conceptualizing the Diarist's Gaze



(Derived from: Kawamura *et al.* (2002) Wearable Interfaces for a Video Diary: Towards Memory Retrieval, Exchange, and Transportation. )

Eight of the nine siblings recorded daily video diaries for two weeks<sup>28</sup>. The video recordings were made in the evening, allowing the widest choice of episodes to be recalled and presented. As with paper diaries, the length of video diaries varied from relatively short (35 seconds) to long (8 minutes). Of a possible 126 daily recordings, the 9 siblings provided 76 diary entries lasting a total of 1 hour 20 minutes. The maximum number of diary entries was 14 (Case 5) and the minimum was 2 (Case 6). The video diaries contained valuable accounts, views and thoughts, offering intriguing insights into their daily life experiences, that I could not have accessed by other means (Noyes, 2005). Although each video diary was unique there were commonalities of structure (see Table 4-4)

Table 4-4 Example of Video Diary Structure

Structure	Example
<b>An opening greeting:</b> The greeting establishes a relationship between the sibling and the invisible researcher as viewer. The greetings developed over time reflecting the 'partnership' between siblings and the researcher.	How are you? I'm G1, brother of G2. It is nice to see you again. (Case 7)
<b>Summarizing orientation:</b> a summarized statement of the day's experience orientating the viewer to THIS day in comparison with other days.	'there is nothing special today', 'today is just like yesterday' (Case 8)
<b>A factual description of the chosen episodes:</b> siblings entry often contained information about specific episodes invariably in chronological order.	This morning I felt sleepy in class. ....after math class, I went to the teacher's room to look for math teacher with my friend.....then, I had dinner at school, I started 'ya-gan-ja-weul-hak-seup' at school. In the middle of night, I heard a fireworks

<sup>28</sup> One sibling (Case 2, aged 7) was unable to make a video diary since she had no private place and no secure space because of the disruptive behaviour of her autistic brother who had broken all the door locks.

	sound.....then I returned home.....(Case 1)
<b>Comments or insights on episodes:</b> diarist's presentation of the episode(s) contains experiences, observations, thoughts, and feelings	Tonight, my [autistic older] brother prepared the bed for us. .... However, he was preparing the bed very slowly....He does everything very slowly ...I am angry whenever I see he is doing things very slowly. I wish he would do things faster (Case 5)
<b>Closing:</b> which indicates the end of each diary	'that's all today'. 'it's time to end' (Case 5)

The opening and closing comments indicated the children's awareness of an indirect observer. Six of the nine siblings included verbal greetings to initiate their diary entries. Noyes' (2004) work on the use of video diaries suggests that it is not possible to ascertain whether the diarist distinguishes the camera as a proxy for the individual researcher or for a wider audience. In my study, however, it was clear that all the participants related to the PMP as a researcher. For example, A1 (Case 1) said '*have you had a good day today?*' or '*I am very sorry I did not make my diary yesterday*' at the beginning in her entry. Although I was not physically present the siblings talked to me through the general or specific description of episodes recorded using the PMP.

The video diary also provided indirect information such as facial expressions, gestures, or wider contextual information that support the researcher in interpreting the spoken word (see Figures 4-3 and 4-4). The added value of bodily behaviour is greatest when participants and researcher are of the same culture. However, care must still be taken to avoid misleading assumptions based on single observations.

This study found that the video diary was less invasive because of the absence of the adult researcher. Researching with children within a Confucianist tradition requires an understanding of the social rules that inform the ways in which direct and indirect forms of communication are used, and in what contexts (Giles *et al.*, 2003). For instance, the hierarchical nature of Korean society inhibits direct conversation between children and adult outside the family. The video diary provided a means of enabling the children to communicate directly, by removing the barrier created by the 'presence' of age difference.

Video diaries were recorded in privacy allowing the participants to express themselves freely. However, two siblings (Case 3, and 5) recorded their diaries in a whisper because they were concerned that their parents might hear.



Overall, the video diary was a powerful tool for uninterrupted self expression and offered unique insights into unexplored worlds. In providing an effective medium to 'give voice' to the siblings of autistic children, the video diary method can reasonably be considered as an empowering form of research.

**Figure 4-3** Watching Baseball Game While Taking Video Diary  
(Case 5, video diary-6, time lap 00:09-00:11)



**Figure 4-4** Facial Expression (Suggesting Irritation) Towards Mother  
(Case 5, video diary-6, time lap 01:42-01:52)



#### 4.6.3.2. *The Home Movie*

Although the video diary is a very useful method to convey personal experiences, it provides a uni-dimensional perspective of events and requires an understanding of everyday contexts and practices (Harrison, 2002). Noyes (2004) argued that “only limited information can pass across the camera interface that connects me to the child and even then there is a translation that takes place as I interpret the data” (p.203). Although video recording provides more contextual data than audio recorded or written data, Walsh *et al.* (2007) observe that ‘video recording needs the context’ (p.53).

Therefore, the current study included an additional approach to gain a greater understanding of the contexts in which described episodes of daily life took place. Self-directed home movies were considered an appropriate way to depict contextual information that is absent from video diaries. Home movies can visualize data in a natural context (Rich & Chalfen, 1999), and offer *thick description* (Geertz, 1993). In a study of young people experiencing asthma, Rich *et al.* (2000) concluded that video is “less invasive than direct observation by researchers and less judgmental than close monitoring or questioning...and may be a more sensitive and specific tool for investigating” (p.162).

Although Chalfen (1987) has warned about the ritualized nature of home movie making, Nicholson (2001:130) argued that if home movies depicted the spaces and places occupied by children, they would expose aspects of current thinking about the realities of everyday family life. In this study the home movies also contributed to the process of data triangulation.

I could find no evidence of the use of home movies as a means to explore the daily lives of siblings of disabled children. However, evolving camera technologies have made the home movie a familiar method. For instance, a number of researchers have attempted to trace the developmental profile of autistic children using home movies. In an attempt to use innovative methods to identify signs of vulnerability in autistic infants in the early developmental stages, Baranek (1999) asked families to make home videos which unintentionally provided additional useful data relating to the autistic child (infant)’s

sensory-processing and sensory-motor development. And Grey & Tonge (2001) compared the early features of autistic children with those of developmentally delayed children without autism through home video.

These two studies have identified important methodological considerations in the use of home videos including variations in quality, duration of filming, and decisions about selectivity for analysis (Bernabei *et al.*, 1998). Holliday (2000) has argued further that “although family movies purport to portray impromptu realities, they more frequently contained acted out scenes hammed up for the camera” (p.515). It is important to bear in mind that home video as a method has been used predominantly with adults and it is possible that child-led home videos can elicit unique aspects of daily family life (Tucker & Matthews, 2001).

In my study, the children were simply asked to ‘show me your daily life’. Eight of the nine children<sup>29</sup>, using cameras for two weeks each, created 110 home movies (approximately 13 hours 17 minutes) showing events throughout the day and including their autistic siblings, parents and other people that define their lives. The children portrayed real life situations, family environments and happenings. Consistent with Maguire’s (2005) arguments that: i) children have good social radar for assessing the situations and contexts in which they find themselves and ii) children’s perspectives and voices are important signifiers of their conceptualizations of their interests, needs, and perceptions, the children in this study were encouraged to select the content and composition of the home movies. Seven of the nine siblings spoke of editing their own movies indicating their sense of ownership of the process of movie making and the final movie to be shared with the researcher.

The movies depicted new ways of framing taken-for-granted everyday life (Bloustien & Baker, 2003). Although the home movie could not convey all aspects of daily life, it was a powerful vehicle allowing access to real daily life that is rarely revealed, and in ways that were defined and interpreted by the children. Figures 4-5 to 4-8 (sources from Case 9) illustrate a day in the real world through the medium of the home movie:

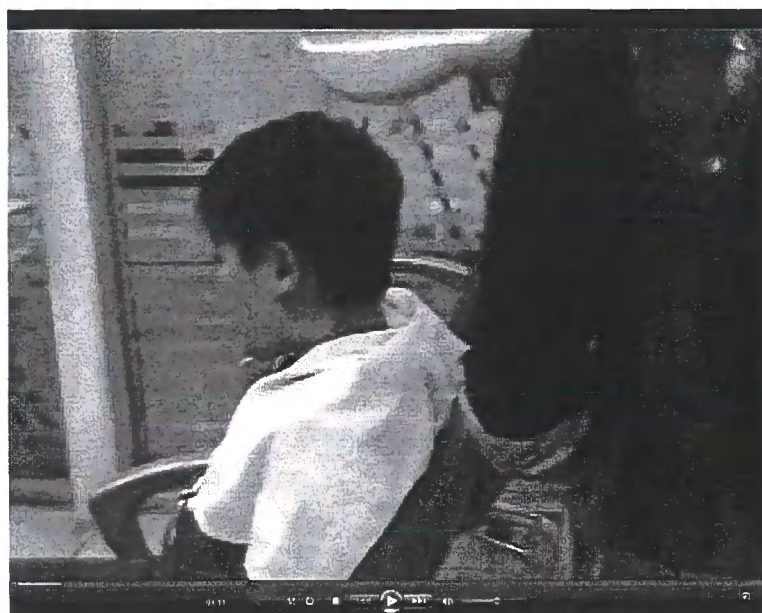
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<sup>29</sup> One sibling (Case 5) did not take any home movies because of his parents’ concerns and camera consciousness.

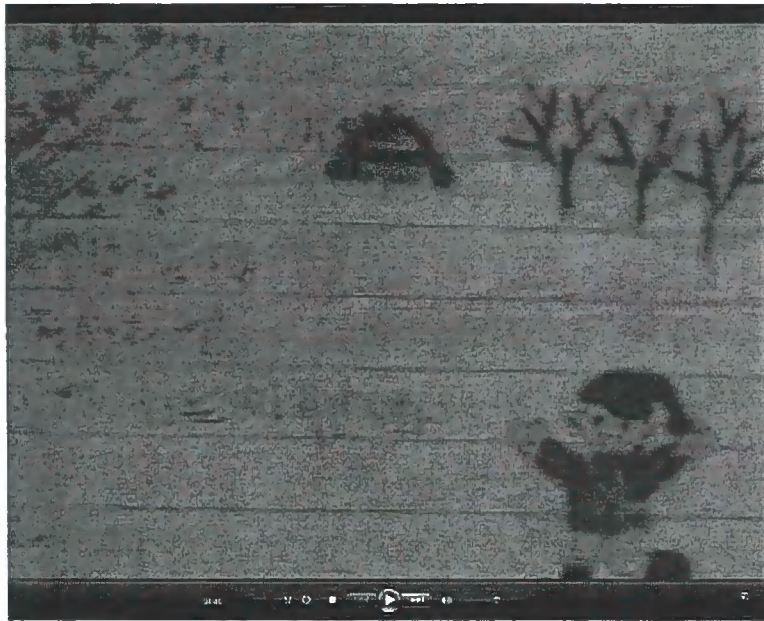
**Figure 4-5** Playing Computer (Case9, home movie 1-4, time lap 02:11)



**Figure 4-6** Cutting Hair (Case 9, home movie 1-6, time lap 03:11)



**Figure 4-7** J2's Homework (Case 9, home movie 1-9, time lap 04:48)



**Figure 4-8** Sleeping with Mother (Case 9, home movie 2-1, time lap 05:03)  
(Mother (left) autistic child (right))



Interestingly, the children reacted differently to the idea of making home movies, even though the study was designed so that they could control all decision making about what, where and when to film. Three young siblings (Case 2, 4, and 6) preferred making home movies to video diaries. Six of the nine children (Cases 1, 3, 4, 6, 8, and 9) took home movies outside the home and four (Case 1, 2, 4 and 6) featured in home movies filmed by parents. This was at the children's own suggestion and was the result of wanting to appear in the portrayal of family life that I was to see. Interestingly, while parents' home movies included interactions between their autistic children and their siblings, they focused more on the autistic child than the sibling. In this sense, methodologically, the self-directed home movie enabled the '*intersection of gaze*' (Lutz & Collins, 1993; cited in Crang, 1997) in which the perspectives of parents as film makers, children as actors and children as film makers intersect, resulting in more integrated representations of siblings' everyday lives.

#### **4.6.4. Data Analysis**

##### **4.6.4.1. Phase One: Interpretation and Ascribing Meaning**

In the first stage, children's video diaries and home movies were viewed to get an overall picture of context and content rather than to conduct a content analysis per se<sup>30</sup> (see Appendix-D), and words simply transcribed into Korean. A simple analysis of caregiving activities was undertaken to describe the nature and range of caring by the non disabled siblings (see chapter 5). Footage in which no clear images emerged, or where speech was inaudible, was noted and the children were asked if they could explain what was happening at these points.

Then, I watched the home movies repeatedly, reflecting on core questions: who was involved, when and where the events were taken, and what was happening in the video

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<sup>30</sup> Although content analysis can give a formal and systematic description of visual images by describing the constitution of defined areas of representation, duration or types of images, it assumes that different viewers can see the same images in the same way (Rose, 2001). Content analysis breaks visual images into parts, seeing each image separately but weighting them equally. However, even a single visual image may have a highly significant meaning and may have complex links to other images. Moreover, Alexander (2001:348) argues that 'content analysis ignores context and the potential for multiple meanings, and it often disguises, through the coding procedure, the investigator's input.' Therefore, content analysis is not the best way for understanding children own images and its interpretations.

(see Appendix-D). The visual images could neither be simply translated, nor understood. As I learnt from the pilot study, care must be taken not to rely only on one viewer's (researcher) interpretations.

In order to elicit deep information, visual data analysis should “encourage children to interpret their own data” (Morrow & Richards, 1996:100). Harrison (2002) also asserted that “asking respondents to interpret images of themselves and/or others elicits processes of ‘making sense’ of meanings assigned” (p.864).

As Holliday (2000) has demonstrated, participants can enable the researcher to discuss questions of self-representation and reflexivity. I wanted to capture children's unique reflexivity and interpretations and reviewing sessions gave the opportunity to share different interpretations of general and specific socio-cultural phenomena. This process of reflexivity involving both child and adult researcher, in turn offers an opportunity to assess intersubjective reliability (Schaeffer, 2003).

The videos required continual re-examination or re-viewing with the children to find accurate meanings. By adopting this ‘*video elicitation*’ approach, each sibling was invited to talk about the video diary and home movie. Before starting, I summarized the process of the reviewing session and reconfirmed their consent. Together, we watched the video with either of us being allowed to pause it at any point to ask questions or add explanation or interpretation about context and content.

In the Korean context, direct conversation between children and adults outside the family is uncommon and socially challenging. The notion of intergenerational respect is deeply embedded in the Korean language with different words being used by, and between, children and adults (Giles *et al.*, 2003). To support the process of elicitation, additional child-friendly interview methods such as finger puppets, drawings and spider-webs were used to gain access to children's insights and also to make the process fun. Although these processes produced significant insights, there remained some unanswered questions about the videos and because of the constraints on intergenerational communication, I was obliged to ask what may be considered leading questions. For example:



- Interviewer:** Here, you said your brother is ‘cute’. Do you mean you love your brother?
- Child:** Yes (Case 4)

However, asking leading questions did not necessarily lead to compliant answers. For example:

- Interviewer:** Before, you said you sometimes could not go out with your friend because of your brother. Do you mean your daily life is controlled by your brother?
- Child:** No, I don’t think so. (Case 3)

Although the additional insights gained from these questions were limited, I have a reasonable degree of confidence that the information was genuine<sup>31</sup>.

All the videos were viewed in this way, an extremely time-consuming process. But this stage was invaluable in enabling the children “to affirm their identity through being able to re-live and share stories about themselves’ with the ‘image making and watching process helping to promulgate the idea of ‘reel’ families as real families.” (Nicholson, 2001:137)

In the final stage, insights from the videos and reviewing sessions were used to explore the experiences of the siblings in focused interviews with their parents. Care was taken to use these insights in ways that did not reveal the content of the siblings’ videos or reviewing sessions. The interviews were recorded, transcribed, and analysed to facilitate triangulation of the data derived from the videos and reviewing sessions.

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<sup>31</sup> On occasions leading questions (e.g. p.147, 185, 210, 224, 255) were used to gain more nuanced understanding of information previously disclosed by the children. Although methodological debate on the use of leading questions in interviews indicates the danger of undue interviewer bias (Crano & Brewer, 2002), it is more understandable in research with children where a) children may experience difficulties with adult vocabulary, or where cultural factors (e.g. strict age hierarchies), or other special circumstances prevail. For example, Hughes-Scholes & Powell (2008), writing in the context of court proceedings, concluded that leading questions are sometimes required in interviews when it is unlikely that the child will engage with non-leading questions. Literature on children’s ‘suggestibility’ (e.g. Quas & Schaaf, 2002) typically focuses on research involving recall of events rather than children’s current understandings.



#### 4.6.4.2. Phase Two

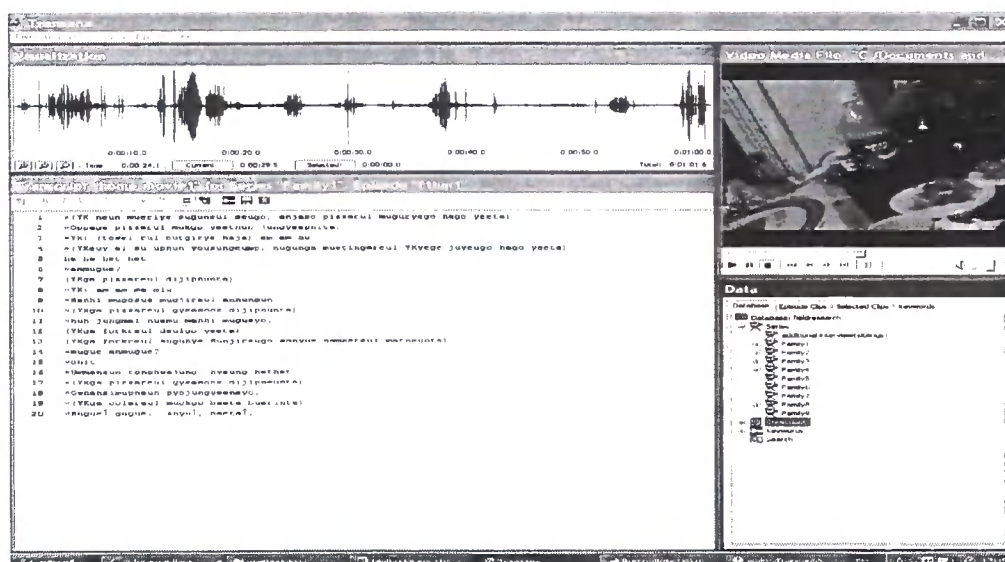
##### 4.6.4.2.1. Video Data Analysis Tool: *Transana*

The analysis of visual material is problematic. Transcription systems have been developed, but some images cannot be decoded into verbal forms (Collier & Collier, 1986:169). A typical analysis method for video is to log the transcription against a framework of time lapses. However, Dicks *et al.* (2006) have questioned “how does a piece of video film change when linked to a piece of written text? And what kind of reading or interpretation is produced by that linkage when the reader can pursue an almost infinite number of traversals and linkages of his/her own?” (p.94).

I had learned from the pilot study that there was no satisfactory software to support the integrating of text and visual images. However, newly developed computer analysis packages such as *Transana* (October, 2001) do allow systematic methods for selecting, coding and itemizing video data to develop.

To solve the daunting challenge of working with such complex visual data, I used *Transana* (version 2.10 see Appendix-E). This permits the simultaneous display of linked visual, audio, and textual material on one screen (see Figure 4-9).

**Figure 4-9** *Transana* Screen Capture Showing (from top left) the waveform of the audio, the video frame, the transcript and the coding frame.



Of the 11 hours 9 minutes of video materials, analysis focused on the footage that had yielded the richest data during the elicitation sessions with the children. In this way I continued to respect the children's roles as interpreters of their own data. Using *Transana*, I viewed the video clip first, and then created a transcript (phonetic English version), and linked places in the transcript to frames in the video. I then attached keywords to those video clips (see Table 4-5). This provided a mechanism for searching and extracting text dependent portions in the video by keywords and by combinations of keywords.

The advantages of using *Transana* over other packages were: i) it offered the most comfortable configuration to enabled analysis of video that cannot be performed with other existing qualitative analysis computer software packages such as *Nvivo 7.0*.<sup>32</sup>, and ii) it was freely accessible<sup>33</sup>. Moreover, *Transana* allows the researcher to:

- Manage large video collections containing long lengths of video
- Create transcripts of videos and link to segments in the video
- Navigate simultaneously through video, audio and textual material
- Apply searchable analytic keywords to video clips
- Store selected extracts (clips) (using a 'quick clip' function, only after version 2.12)
- Make maps to display a series of episodes in order to compare the sequence and distribution of keywords across a series of episodes (after version 2.12).

All formats of data were digitalized, facilitating the logging, accessing and transferring of data for, and during, analysis. Nevertheless, I encountered a number of difficulties and challenges:

First, *Transana* is currently limited in its capacity to move keywords derived from any of the three data sources (visual, audio and textual) and in its capacity to move data extracts as supporting evidence.

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<sup>32</sup> Nvivo 8 (due for release in April 2008) will support analysis of visual and audio data.

<sup>33</sup> But it was not open source from later version 2.20.

Second, *Transana* is also currently limited in its compatibility with visual data formats. This meant that I had to encode all the video footage using *Adobe Premiere* which resulted in reduction of image quality and the loss of some visual data, although the most serious loss consisted of 30 seconds from a one hour file.

Third, *Transana* does not currently support the use of Korean language characters. I therefore had to transcribe Korean speech in Roman script (see Appendix-F). This process was very time-consuming.

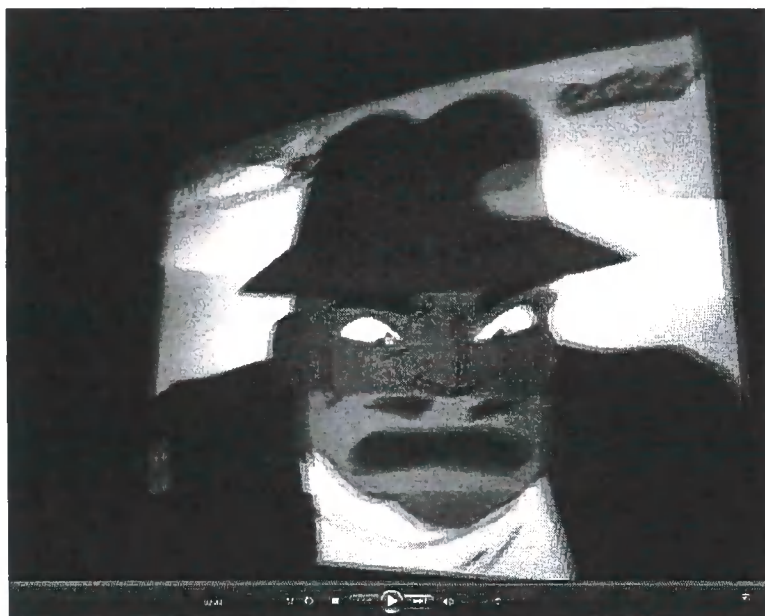
Lastly, I experienced difficulties exporting and importing visual data (so that transcriptions, timelines, video clips, and keywords failed to match accurately) which limited the flexibility of being able to work on different computers.

#### **4.6.4.2.2. Analysis**

My analysis relied on a process of induction, with no predefined theoretical perspective. In the first stage, I adopted the approach of video data analysis (Morse & Pooler, 2002): play and replay, speed up, slow or pause, analyse, reanalyse, and noted insights. Identifying, selecting, classifying and categorizing the video clips was achieved using *Transana* (ver 2.10). *Transana* facilitates the line by line linking of transcripts, video and audio data permitting a seamless process of ‘reading’ the data. Selected video clips were placed within the ‘Collection’ facility retaining details of timing, keywords, comments, and file location of any footage.

An initial stage of data management involved filtering out poor quality images, for instance where a child filmed only a television programme for seven and a half minutes, or where the screen was entirely dark. Approximately ten percent of the home movie footage was filtered out in this way. (e.g. Figure 4-10, Figure 4-11).

**Figure 4-10** Source from Case 6 Home Movie-8 (filming TV Cartoon, time lap 01:40-09:17)



**Figure 4-11** Source from Case 2 Home Movie-2 (Dark screen, time lap 01:57- 03:15)

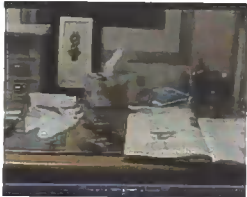



Initially, I followed an open coding approach associated with grounded theory (Strauss & Corbin, 1998; Glaser, 1992): achieving an overall sense of keywords and categories through the videos and children's commentaries. The video diary, home movie, reviewing session and parental interview were organized by case and open coded (See Table 4-5). This coding was the first level of conceptualizing the data and reflected the language of the participants (*in-vivo* codes) as well as the data. In this stage, a significant numbers (31 keywords with 341 sub-keywords) of keywords were produced. This was followed by a new search to identify any missing Keywords and to see how existing keywords related to one another (see Appendix-G).

It was only at this point that I made the transition from Korean to English, and translating only the data that served to illustrate or inform the final sets of keywords. I used 'back translation' techniques (e.g. Brislin, 1970; Kim & Lim, 1999; Yu *et al.*, 2003; Harkness, 2003), by working with two bilingual (Korean/English) colleagues, to validate the meanings of the keywords in English and Korean. This allowed for checking the accuracy of the translations of words and concepts (see Appendix-H).

Using the identified keywords, all cases were compared in relation to birth order, gender, familial and socio-cultural aspects. This comparison helped to identify commonalities and differences between families.

**Table 4-5** Example of Keywords Drawn from (four) Different Sources of Data Relating to The Same Case

Children's video		Children's comments on their videos	Parents' interview	Keywords
Video diary	Home movie			
 <p><i>'My brother, J2 has good and bad days. I wish to recognize his mood as fast as I can, so that I know how to deal with him well. I hope to be a good brother for J2.'</i> (J1's video diary-5)</p>	 <p><i>Today, J2 said 'bae' (pear) to me. I did not know what he said. I realized he wanted me to peel a pear. I have never peeled a pear before. But I peeled the pear for J2 today and he was happy</i> (J1's Home movie-5)</p>	<p>(In the reviewing session, we watched J1's home movie in which his autistic younger brother, J2, has a 'tantrum' related to his insistence on being given a specific jelly for a snack. J1 goes to the shop to buy the jelly with J2)</p> <p><b>Interviewer:</b> Can he go to shop to buy snack by himself?  <b>Child:</b> Yes, he can do but he would like to take many items and he throws the money on the street, and he does not know the price.  <b>Interviewer:</b> Do you go with him [of your own accord] ,or do your parents ask that you go with him?  <b>Child:</b> If he has money he thinks about going to the shop. But he does not know he should pay. If he shouts 'ice-cream', mother gives him money. I follow him, sometimes I see him throw the money on the street.  <b>Interviewer:</b> You mean, you always have to look after or help him?  <b>Child:</b> Yes  <b>Interviewer:</b> Do you help him because he is your brother or because he is disabled?  <b>Child:</b> My brother needs helps  <b>Interviewer:</b> Is that difficult for you?  <b>Child:</b> No, it's part of life every day.</p>	<p>'He (J1) told me about caretaking. We never said 'you should take care of J2', because he might feel this as a burden. So, as mum and dad we will take care of J2 continually, although we don't know what will happen in the future. We never asked what he feels he has to do. Although we never said 'you should take on the role', he might feel a deep sense of obligation. He said 'My wife and I will have to earn plenty of money so that we can pay for a paid-caregiver for J2, so that I can take care of him' ..... Then we realized he felt his brother was a really big burden. For me, I appreciate his willingness to accept this obligation (J1's mother)</p>	<p>Gender            Birth order            Role            Future-demanding            Obligation            Care            Good sibling</p>

#### 4.6.5. *Validity: the Use of Reflexivity*

A central concern of my study was to transform and interpret the visual data as rigorously as possible. Scientific rigour is critical to qualitative research which can be assessed in various ways (see Kirk & Miller, 1986; Sarantakos, 1998; Bryman, 2001). For example, Lincoln & Guba (1985) propose alternative criteria for establishing trustworthiness in qualitative enquiry such as, 'credibility' (internal validity), 'transferability' (external validity), 'dependability' (reliability) and 'confirmability' (presentation).

The crucial question for my study is 'can visual data be considered as valid?'

Methodologically, Kirk & Miller (1986:30-31) have argued that qualitative research has an 'in-built sensitivity' which creates a kind of 'automatic validity' because, in the field, research is 'controlled by the investigatees rather than investigator'. In particular, LeCompte & Goetz (1982:43) argued that the major strength of ethnography may be validity. Indeed, the video footage provided images of real activities in real situations offering 'truth value' (Jones & McNamara, 2004:281). As Dufon (2002:43) pointed out:

Video can give us a more complete sense of who the people are, and acquaint us with the setting in which the people function and the types of activities they engage in from day-to-day as well as the nature of these activities themselves

Visual methods can also offer additional possibilities to illuminate realities, perceived participants' thinking and understandings that text-based data alone might not reveal (Richards, 2006). But we must remember that the 'reality' of the visual images (Lomax & Casey, 1998; Denzin, 1997; Pink, 2001a; Fasoli, 2003) is defined by the 'image maker'. For instance, Morse & Pooler (2002) have suggested that a scaffold analysis approach<sup>34</sup> can avoid threats to validity in observational research. But this approach still relies solely on the researcher, using variables prescribed by the framework, targeting observations and controlling what is regarded as pertinent and relevant. A reflexive understanding is required. Rose (2001:15-16) and Mason (2005:330-331)

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<sup>34</sup> In analysis of sole source video data, the researcher continues to work inductively: describing behaviours, questioning observations, verifying and confirming, and systematically creating or extending theory.

argue that a critical approach to visual images needs to: 'take images seriously' (visual narrative), 'think about the social conditions and effects of visual objects' (context), and 'consider viewers' own ways of looking at images' (reflexivity). Validity of visual images, or their interpretation, may be enhanced by allowing for validity checking by a number of viewers. This approach was strictly limited in my study because of the strict confidentiality undertaking with siblings and their families. In distinguishing traditional validity and reliability from scientific realism, Pink (2001b) argued that what is crucial is reflexivity and recognition of the context which produces an image and, in turn, ethnographic knowledge:

Rather than being a method for the collection of 'data,' ethnography is a process of creating and representing knowledge (about society, culture and individuals) that is based on ethnographers' own experiences. It does not claim to produce an objective or 'truthful' account of reality, but should aim to offer versions of ethnographers' experiences of reality that are as loyal as possible to the context, negotiations and intersubjectivities through which the knowledge was produced.

(p. 18)

My study makes use of the biographic-ethnographic context of children's individual experiences and the authority of their own sense of personal meaning. Reflexivity played a key part in constructing 'reality', as the siblings reflected on the visual material they had captured. Reflexivity can refer to an awareness of the ways in which the researcher and the research process may have influenced the data generated and the interpretations made (see discussion in Pink, 2001a). Contextual validity<sup>35</sup> in particular is easier to achieve in video than photographic images because video or film contain continuity, movement, and contextual information (Prosser, 1998:106). In this study validity is constructed by integrating reliance on participants' interpretations of their visual images with the researcher's constant self-monitoring; called '*video-elicitation*', rather than by simply relying on the researcher's own reflexivity and interpretation. Moreover, threats to validity were reduced by careful construction of the parents' interviews to elicit information about the context and content of visual data and

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<sup>35</sup> Prosser (1998:104-106) argued that the trustworthiness of moving and still images depends on their contextual validity; the context of 'making' and 'interpreting' images. Judgements and claims of contextual validity are made via reflexive accounts, but also through representation.

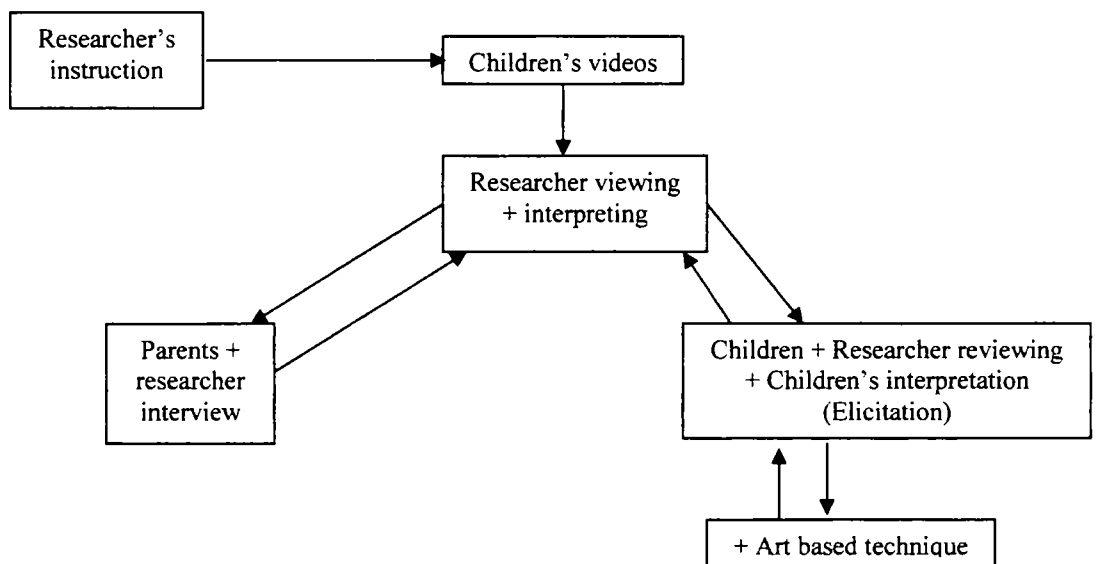


children's interpretations. In working with the siblings as active researchers, videos were viewed as open works to be reinterpreted, reflexivity was taken seriously and I was placed in the position of being both 'insider' and 'outsider' (Jones & McNamara, 2004).

#### 4.6.6. Credibility

In qualitative research, in which results cannot be generalized due to the uniqueness of the experience (see Ashworth, 1997), credibility may be established through participants' confirmation that the data truly reflect the phenomena as they perceive them. Triangulation of data also contributes significantly to the credibility of findings (Patton, 2002; Cutcliffe & McKenna, 1999) and confirms the authenticity of the study's observations and subsequent findings (Lincoln & Guba, 1985). In this study the perspectives of siblings, parents and the researcher were triangulated (see Figure 4-12) to establish a degree of trustworthiness.

**Figure 4-12** Triangulation Involving Multiple Data Sources and Methods



Therefore, in addition to the reviewing sessions of the video diaries and home movies, which relied on verbal interchange, I used art-based activities (e.g. 'fish in the net' technique, family pictures and spider-webs) with the seven children to offer additional insights and supplementary contextual information in ways that did not rely on verbal

articulation (see Diem-Wille, 2001; Deacon, 2000; Burkitt *et al.*, 2003; Kendrick & McKay, 2004). These activities enabled the children, who used an indirect conversation style, to describe complex issues and to interpret the social structures and relationships that affect their lives (Thomas & O’Kane, 1998:342). Analysis of these drawings provided themes comparable to those derived from the other data sources, confirming children’s interpretations of the visual data and parents’ perceptions of their children’s experiences.

## 4.7. Ethical Considerations

### 4.7.1. Informed Consent

Informed consent is the central ethical issue in research involving children (Dorna *et al.*, 1995; Miriam *et al.*, 2001). In particular, informed consent is one of the most difficult ethical issues in visual research. Kellett (2005a) summarizes the ethical issues involved in the use of video recording:

Informed consent is especially important because anonymity is more difficult to achieve for video work. It is not easy to disguise the identity of people on video. They may even refer to each other by name. For this reason, confidentiality becomes especially important. Research videos should be kept in a safe place, and they should be deleted...unless they [researchers] have specific permission to use a sequence. (p.55)

Ethical clearance for this study was granted by the School of Applied Social Sciences Ethics sub Committee. Details of the ethical approval process and the application form appear in Appendix-I.

Working with children directly in research begins with seeking their active consent to participate. In Korea, there is no legal requirement for children to consent to participate in research, with parents as ‘gatekeeper’ being able to give consent. However, I argued that the children must have the right to decide whether to take part or not (see Masson, 2000). As a result, I asked for children’s as well as parents’ informed consent to

participate and asked them to complete a form if they decided to join the study. The form made it clear that the children could withdraw at any time, and indeed four children did withdraw after initially agreeing to take part. The consent forms did not include arrangements for disclosure of information in circumstances where the autistic children or their non-disabled siblings were perceived to be at risk of harm. Although the issue of child maltreatment and neglect has received public attention and child protection laws<sup>36</sup> have been enacted in Korea (Hahm & Guterman, 2001), the concept of child abuse within the family and public intervention in private family matters for the sake of child protection are still generally unacceptable to Korean families (Chang *et al.*, 2006) With the continuing power of the traditional culture, disclosure of an individual's problems and private family issues to an outsider are perceived as a sign of weakness that brings strong shame and disgrace to the family in Confucian culture (Farber, 2006:93). As a result, I approached the question of disclosure of intrinsic harm or intrinsically harmful practices (Ncube, 1998) separately from the written consent forms, since inclusion in the forms would have run the risk of alienating families who were otherwise interested and willing to participate in the study. I explained carefully to the children that their video diaries and home movies would not be seen by anyone other than me and my university supervisors. But, if I noticed that they, or their autistic brother or sister appeared to be very sad, very unhappy or very upset, I would first discuss it with them and might need to let their parents know. But I would not tell their parents without i) first discussing with them, ii) then encouraging them to talk to their parents themselves. I also discussed with each family unit (parent(s), their non-disabled children and their autistic siblings) that any concerns I had about any incident that might indicate harm to any of the children would be discussed first with the children before discussing with the parents in order to reduce any risk of harm to the children. As Yang S.N. (2008) has argued, the moral principles and values of Confucian familism, grounded in strong ties of affection and respect within the family are recognized to play a protective role for children. Although this can be no guarantee of absolute protection, faced with the challenge of applying the ethical principles of research from one cultural context to fieldwork in a different cultural context, my concern was focussed on maintaining engagement with the families who were willing to participate in the study, while at the same time ensuring that 'cultural sensitivity' did not lead to unquestioning

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<sup>36</sup> But there is no equivalent legal procedure of a Criminal Records Bureau (CRB) check in Korea.

acceptance of any practices that may have been intrinsically harmful to any of the participants (Ncube, 1998; Archard, 1999)<sup>37</sup>.

I provided the children and their families with sufficient time to consider whether or not they wanted to participate in this research. Encouraging children's involvement in decision-making reflected a respect for their rights (UN, 1989). Although legal requirements for children's consent may rest on their full understanding of whatever they are consenting to, the consent of children in this study was sought at every stage. As discussed in 4.4.1, I made attempts to reduce discrepancies in power and status between myself as an adult researcher and children (Morrow & Richards, 1996) by including children as active researchers with clearly defined power and status. For example, the children had control over the times and locations data collection, as well as being involved in the analysis of data.

The question of power dynamics within families also gave rise to tensions between the children and their parents. I was not able, nor had I the right to resolve unexpected tensions that occurred within families as a result of the research process. While the children agreed to participate in the research, I was mindful that it can be hard to disagree with the parents' decision to participate. I therefore stressed that all participants had the right to withdraw from the research at any stage.

Finally, I originally considered seeking consent from all family members who appeared in any videos. The autistic children in particular were present during all family discussions of the research and the use of video equipment, and I gave serious consideration to the question of consent from the children with autism who were indirect participants in this study, featuring in the home movies filmed by their siblings. But little attention has been paid to the issue of gaining disabled children's consent to participate in research in the Korean context (Kim and Kang, 2003). In this study, obtaining informed consent from the autistic children presented the biggest challenge. Many researchers view it as possible and preferable to provide information in appropriate ways that enable 'vulnerable' participants to understand what participation

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<sup>37</sup> Ethical concerns during fieldwork were subject to discussion with my supervisors. However, no major ethical issues arose and the focus of discussion related to ensuring that the siblings did not impose unwanted filming on their autistic siblings.

will involve whatever their level of ‘capacity’ (Alderson & Morrow, 2004; Alderson, 2004; Goodenough *et al.*, 2004; Fisher, 2003; Christiansen & Prout, 2002; David *et al.*, 2001; Casarett & Karlawish, 2000; Edwards & Alldred, 1999; Rodgers, 1999, Stalker, 1998; Scott *et al.*, 2006), along with the presentation of innovative methods such as recording and drawing (Connors & Stalker, 2003; Alderson, 2004; Wiles *et al.*, 2005). Nevertheless, the ability of vulnerable people, particularly children, with mental health problems or learning disabilities, to give informed consent remains contentious (see Wiles *et al.*, 2005).

Obtaining consent was informed by questions of cultural sensitivity and the central role of parents as guardians of autistic children’s decision making in Korean society. The first consideration in gaining informed consent for the autistic children was linked to the cultural implications of drawing further explicit attention to their degree of disability that would add to the humiliation and shame already experienced by each family. I had to bear in mind that, although I had gained sufficient trust of each family to give me a privileged position in accessing the experiences of their non-disabled children, I was still obliged to show the utmost respect for social and cultural boundaries. For instance, there were areas of family life that it would have been unacceptable for me to question such as the quality of relations between the parents that is considered intensely private. Drawing *direct* attention to their children’s impairments would have been similarly unacceptable. Gaining consent for the participation of the autistic children was therefore left to the parents. This approach reflected the parents’ better knowledge of their autistic children’s understanding, but also the protective approach of parents towards their autistic children.

I explained my expectations of their autistic children’s participation, i.e. that this should be voluntary and that they should not be put under pressure to comply. All parents gave their consent freely, while principles of ‘assent’ (Ferguson, 1978) were followed for the autistic children. The children and their parents were agreed that the home movie should only be filmed when the parents were present and carefully monitored autistic children’s reactions. Where autistic siblings showed any sign of distress or objection, the children were asked to stop filming immediately to ensure that filming did not cause distress or harm to the autistic children. Use of video footage in this thesis showing the autistic

children has been subject to the additional consent of parents and anonymisation (by covering key facial characteristics). Moreover, some images of autistic children, which were taken by their non-disabled siblings to show their daily lives to the researcher, were omitted from the thesis despite parental consent since there was a possibility for misinterpretation by readers from other cultural contexts.

#### **4.7.2. Privacy and Confidentiality**

Other ethical considerations in relation to visual research concern individual privacy and confidentiality of data (see Rich & Chalfen, 1999; Schaeffer, 2003; Aldridge, 2007b). This study involved very private individual and family experiences of living with autism. The home as a private place is a difficult location for research (Hood *et al.*, 1996) with a potential for loss of privacy. The main concern was that the siblings and their parents would be reluctant to reveal their experiences and feelings. Making home movies had the potential to disturb power relations between children and parents. Four children decided to withdraw from this study and in keeping with the conditions for gaining informed consent, I accepted their withdrawals unquestioningly. They did not explain the reasons for withdrawing although I observed that in two cases the parent became ill, and in the other two, tension was evident in the relations between the siblings and their parents.

The need for privacy was paramount given negative cultural attitudes towards disability. In the initial meetings families were given full information about the study and its methodology, including the use of video that would be controlled by, and confidential to, the children. Respecting principles of privacy and confidentiality (Daniels, 2008), the families were reassured about protecting their identities, secure storage of data and confidential treatment of data (see Appendix-A). Participants' consent was sought again before any use was made of (still) images in the thesis, and these were emailed together with accompanying text to the parents who were asked to discuss, together with the children, consent for their use in the thesis. It should be noted that parents were present during the making of the home movies, so they were not being giving access to material that was private to the children. In two cases, I was asked to substitute particular images of participating children for others, which were approved by the children and their parents before inclusion in the thesis.

The use of video presents significant challenges for public confidentiality and social network confidentiality (Hill, 2005). In my study, public confidentiality was guaranteed by secure storage of password protected files, by limiting viewing of the video data to the children, me and my academic supervisors, and the limited use of images from the video through still images in which identifying facial features have been obscured. No further use of the images is permitted without permission from the children and their parents. I was also careful to avoid questions of unjustified invasion of personal privacy when the children filmed in public places (Pinks, 2001b). Given the impossibility of obtaining consent from unknown members of the public (Holm, 2008:332), it was agreed with the children and their parents that filming should be restricted to family members and environmental contexts. When filming in public spaces (e.g. corner shop, big grocery market, restaurant, hair shop, park), the children stopped filming if strangers entered the range of the camera. Non family members did appear on 5.4% of total video footage. In no case was it possible to identify individuals and no use was made of this footage.

A further consideration for social network confidentiality concerned the involvement of parents in the study in existing support networks from which the families had been recruited to the study. Despite clearly explaining the rules of confidentiality to each family individually, two parents who knew each other well and had shared the fact of their participation in the study, contacted each other to discuss how their children could make the video diaries and home movies. Although the parents' intentions were to support their children in producing high quality videos, I explained that any discussion of their children's participation ran the risk of breaching the confidentiality agreement that we already reached. The parents understood and no further discussion between them took place.

Interestingly, the children in these two families did not discuss their participation in the study and appeared very relaxed about getting on with recording their experiences. More generally, during the interviews with parents it became clear that they were all interested to know what their children had said. Their interest was motivated not by the intention to interfere, but was based on their positive response to the research. It seemed that the questions being posed by the research had not come within their sphere of thinking before. And they embraced the opportunity to gain a deeper insight into the

experiences of their non-disabled children. Despite their positive motives, I had to remind them that I had undertaken to maintain the confidentiality of their children. This was imperative because DVDs of the children's visual data were given back to the children and both video and audio records can be easily recognized by others within the same social network (Rich *et al.*, 2000). All the parents were able to reflect on this, recognise the importance of their children's privacy and made no further attempts to obtain information about the children's views from me. The parents' interest was identified by eight of the nine children who sought reassurances during reviewing sessions that their videos would not be shown to their parents or others. I was able to give these reassurances in relation to my own handling of the film and data. But I also reminded them about: i) the importance of keeping their video diaries and home movies safe to avoid the possibility of being located and viewed by others, and ii) not sharing them with others in order to maintain family confidentiality and to avoid any possible negative consequences arising from cultural stereotyping or stigmatizing reactions. The children had already sought assurances that their films would not be shared with their parents and I made use of these concerns to reinforce the importance of the children's personal confidentiality. I explained that their parents understood the importance of individual confidentiality, and undertook to honour the privacy of the children's films.

Fieldwork with each family was concluded by a meeting with each whole family when we had tea together and discussed any outstanding issues and direct families to sources of support if necessary. The families had been recruited to the study through parent support groups however the study revealed that neither the autistic children nor their non-disabled siblings were receiving social or therapeutic support outside private, one-to-one, special education provision for the autistic children. I took advantage of my own professional networks to provide information about available and newly emerging support services, including support groups, both for autistic children and for the siblings of disabled children. I left information leaflets with details about services including contact information.

Although the families had my email contact and they knew that they could communicate with me I was clear with them that I would be returning to the UK and would not be in position to provide any support myself. I have received greetings from five families and am aware, from subsequent communication to confirm permissions to



make use of still images from videos, that all families have made contact with some of the support services I informed them about.

#### 4.7.3. *Gender and Age*

Literature, in Western contexts, suggests that children are able to discuss sensitive topics which have significance in their day-to-day lives, such as family relationships, domestic violence, disability, AIDS, sexuality and death (e.g. Pettle & Britten, 1995; Moore *et al.*, 1996; Cree *et al.*, 2002; Mullender *et al.*, 2002). However, researchers should carefully consider children's developmental stage and gender.

These considerations were also important for the reviewing sessions in my study. I needed to be aware of the impact of differences between me and the children, and the need for privacy in discussing their video footage. For example, it is possible that the five girls in my study may not have felt comfortable with me as a male adult researcher. In order to allay children's and parents concerns I asked the mothers to ensure that they were nearby, but still allowing enough distance to offer their children privacy. I also took care to explain to the children, both at the beginning of the study and at the time of the reviewing sessions, the purpose of the sessions and to reassure them that they could stop at any point, either for a break, or even to withdraw from the process.

Although these measures resulted in successful reviewing sessions with all participating children, there were examples of children's anxiety. For instance, one of the elementary school aged girls (Case 4) brought a bamboo model of kendo sword with no blade to a reviewing session with her. Her mother was in a bedroom on the same floor, but she explained the significance of the bamboo sword as being for her protection<sup>38</sup>.

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<sup>38</sup> On my first visit to D1's home to undertake the reviewing session, D1 explained she did not want to watch her video and asked me to come back another day. On my return, D1's mother made tea for us all (D1, D2, their mother and me). We had a general conversation and discussed D1's day at school. D1 confirmed that she was happy to watch her video with me and D1's mother left the room with D2, but the door remained open. As I set up the monitor D1 left the room and returned with a bamboo model of a Kendo sword with which she was playing. She showed me some of the moves she had learned in lessons at *Hakwon*. I commented on her skills and then asked if she could put the model sword down so we could start the reviewing session. D1 did not respond so I asked if she would prefer not to watch the video. She replied that she did want to watch the video now but she also liked doing Kendo practice. I suggested it was difficult to do the two things together. And to be certain that she was not feeling pressurised to watch the video I asked her mother to help interpret D1's response. D1's mother asked D1 if she was happy to

Parents also expressed concern about conducting research in a private place with their daughter, especially adolescent girls. For instance, when conducting a reviewing session in Case 8, the participant laughed loudly. But her mother guessed she was crying and came to check immediately. Hill (1997:179) commented that “there are circumstances in which girls are more forthcoming to female interviewers and boys to male interviewers”. Therefore, although the reviewing sessions with girls were carried out in privacy, I specifically asked parents to be close by allowing easy access if necessary. During these sessions, the door was left ajar but parents were not able to hear the conversation. All reviewing sessions were also video-recorded with permission of both children and parents.

A further issue is ‘*culture of communication*’ (Christensen & Prout, 2002:483), which refers to differences between adults’ and children’s communication styles. Korean children in general are not used to expressing their innermost thoughts, feelings and complaints (Choe, 2001). More particularly, gender is directly related to communication style (Lee & Ok, 2002). This may lead to embarrassment during my viewing of the video and discussion of sensitive issues including parents, nudity, and autism. The three younger girls found it difficult to respond in the reviewing sessions when the video material revealed information about sensitive issues, even though I stressed that they were free to say, or tell me, whatever they wanted. Where there was reluctance to speak, I attempted to elicit information by encouraging them to speak, even using leading questions (see section 4.6.4.1). This also can present its own challenges, as it is difficult to return to free narrative after the use of leading-questions (Gilstrap, 2004). In order to avoid this problem, I reverted to an informal and child-friendly conversational style, in some instances playing with the children, during reviewing sessions. I followed Morrow & Richards’ (1996) suggestion that the adult researcher should avoid asking questions about issues which could confuse and upset children.

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watch the video and D1 replied ‘yes’. Her mother suggested that it would be better to put the sword away in her room and D1 responded by handing the sword to her mother. My interpretation of this incident is that 8 year old D1 may have been experiencing some anxiety at the prospect of watching the video with me. But following reassurances from me and her mother that she did not have to watch the video if she did not want to, she then agreed. I reassured her that she could stop at any time. Over the course of watching the video we took regular breaks from viewing, approximately every fifteen minutes. During the breaks D1 asked to play with finger puppets that I had brought with me. Her mother remained in the background elsewhere in the house and passed through the room where I sat with D1 on three occasions.

#### ***4.7.4. Ensuring No Harm to Participants***

Visual ethnography presents additional challenges in relation to ethical considerations. Pink (2001b) argues that harm and anxiety must be understood from the informant's perspective in the research context. The children in this study showed embarrassment when watching sensitive scenes (e.g. naked autistic child, parent's aggressive words) in the videos although, interestingly, they had not edited/deleted these scenes from the videos. This suggests that the children felt ownership of the video. Indeed they had deleted video footage before the end of the two week period, and in the reviewing sessions, five children (Cases 3, 5, 7, 8 and 9) referred to the process of editing their videos.

It is important to remember that the process of filming and deciding what to film is an emotional as well as a technical process, and this can have an impact on the representativeness of the data. Beresford's (1997) study with disabled children, suggested that children involved in research may feel emotional distress such as fear of failure, threats to self-esteem, reactions to invasions of privacy, conflict, guilt, or, embarrassment. And Hill (2005:73) also argued that researching sensitive topics may lead to children's distress.

My study dealt with very sensitive and private topics and many video segments contained scenes that would be disturbing to outsiders, and cause embarrassment to the children. I had to be very careful in the reviewing sessions with the child participants to ensure that they were not left with feelings of regret or resentment about their own videos. This involved responding sensitively to any signs of distress, giving the children a break during the session and reassuring them that the footage would not be seen by anybody other than them and me (and my academic supervisors who were presented as being from another culture and having little knowledge of Korea). In these ways I was careful to ensure that the keenness to take videos would not adversely affect family relationships or run the risk, directly or indirectly, of causing harm to the children or their autistic brothers and sisters.

The experience of the pilot study had shown me that all the child participants were potentially at risk from physical, verbal and/or emotional aggression from their autistic siblings. In any piece of research with children, concern for their safety and well-being is of paramount importance. In the field, video-making increased the physical risk to the children if their autistic brother or sister had highly aggressive behaviours. When the PMP was loaned to the children, they all hid it immediately to avoid the risk that their autistic sibling might take, or break it. I also explained to the children that if they felt uncomfortable they should stop filming and if necessary, remove themselves from the setting. Although it was not possible to foresee every possible consequence of filming for the children, I made explicit attempts to prevent the children being placed in difficult situations as a result of participation. Similarly, as discussed in 4.7.1, measures were put in place to ensure that no harm came to the autistic children who were commonly actors in their siblings' home movies.

#### **4.8. Summary and Conclusion**

In this chapter I have discussed a wide ranging set of methodological considerations in preparing for the data collection phase of the study. As well as discussing the use of innovative methods of data collection and analysis I have addressed the challenges and opportunities of working with children as active researchers and the ethical considerations that are particularly important in working both with children and disabled children.

The following four chapters present the findings of the study and address, respectively, meanings, understandings, daily life experiences and vulnerabilities of the siblings of autistic children.

## **Chapter Five**

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# **The Meaning of Being a Sibling of an Autistic Child**

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## 5.1. Introduction

In this chapter I explore the question of what it means to be the sibling of an autistic brother or sister in Korea, focusing on children from two families to illustrate sibling experiences. These participants provide unique insights that consistently demonstrate sacrifices for the autistic sibling related to the complex and diverse nature of filial obligation.

I begin by exploring the ways in which this ‘sacrifice’ is sustained through expectations associated with birth order and gender, drawing on children’s accounts of the effects of the presence of an autistic brother or sister, how this alters the normative expectations associated with children’s roles and responsibilities, and the impact this has on their self identity. Next, I examine the long term implications of these disruptions for the normative expectations associated with sibling roles and responsibilities. Finally, I present parents’ accounts and perceptions of the experiences of their normally developing children<sup>39</sup>,s roles and responsibilities towards their autistic siblings.

## 5.2. Snapshot from Fieldwork

In this section, two cases are used to illustrate the links between birth order, gender and ‘sacrifice’. Case 9 is J1, a thirteen year old boy, the elder brother of ten year old J2 who is autistic. They are from a high income family, and have moved to an expensive region with access to special school provision for disabled children. Case 8 is H1, a thirteen year old girl, the elder sister of H2 an eleven year old boy who is autistic. They are from a low income family. H2 was born in Thailand, where his father worked as a Christian missionary, and was diagnosed with autism on their return to Korea. Both J1 and H1 made use of their video diaries and home movies to offer detailed accounts of: i) their everyday lives as siblings of autistic children over a substantial period and ii) their thoughts and expectations for the future.

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<sup>39</sup> In the context of this study, ‘normally developing’ children refers to the siblings of the autistic children

### *5.2.1. Case 9 (J1) Background*

J1 attends middle school (year 1). His autistic younger brother, J2, is in a special education class for children in need at elementary school (year 1). Both children were born in Korea but because of their father's work they lived in Japan and the USA before returning to Korea three years ago. J2 has extreme difficulty communicating using verbal language. He consistently demands 'aisha' (a specific brand of) jelly and strawberry ice cream throughout the day and night, having a 'temper tantrum' if he is refused. J2's disturbed sleep patterns have a direct impact on J1 who shares a bedroom with him.

J1's father is 41 years old, and works in the Court. His mother is in her late thirties. She was an English teacher in a secondary school, but quit her job when J2 was diagnosed with autism. Her attention is focused almost entirely within the family, specifically on J2. She has experienced the stigma of J2's autism, but religion (Christianity) provides an important coping strategy.

A Korean family they met at church while living in the USA, and with whom J1 has spent vacations since returning to Korea, has helped J1 understand the implications of having an autistic brother, for example why his mother has little time for him, and to accept the responsibilities of being an older brother. J1's mother discovered that while visiting another family in the United States, J1 had confided some negative feelings about living with his autistic brother, feelings he had never revealed to his own parents. The mothers from both families had spoken and J1's mother realized, for the first time, that he experienced some difficulties. She was shocked by this.

Since attending a new middle school J1 had made new friends. These friendships had introduced some tension into the family as J1 sought independence and made new demands on his parents. For example, he quarrelled seriously with his parents about accessing an unlimited text messaging service. And, without his parents' permission, he went to an internet café with friends. But now, J1 behaves as a caring brother to J2, sharing a bedroom, accompanying him outside the family home for shopping and

exercise. He accepts J2's behaviour without complaint, but keeps his school friendships separate and has not talked about his brother or family life with his friends.

### *5.2.2. Case 8 (H1) Background*

H1 attends middle school for girls (year 1). She has a very positive outlook on life and is very talkative. But she prefers to talk with friends rather than her parents about personal issues. Generally, she has a good relationship with her autistic brother with whom she shares a bedroom. However, she emphasizes that individual life is more important to her than her autistic brother. She does not want to change her life because of H2. She resents the fact that the family moved back to Korea because of her brother's autism and she would prefer to live in Thailand again.

H2 attends a special education class (year 5) in elementary school. He has difficulty communicating using verbal language. Typical behaviours include playing children's internet games, repetitive washing of his hands and face, a fascination with striking matches and a need to be snacking continually on sweets, ice lollies and biscuits.

Their father is in his mid forties. After completing post-graduate study, he became a missionary and worked in Thailand. But he gave up his job because of H2's autism and returned to Korea where he has started a further post-graduate degree course at a theological seminary.

Their mother is also in her mid-forties. She works as a school dinner nanny. Her own older brother has (non autistic) learning difficulties. Although he lives in a residential care home, she still supports him financially. This is an additional burden that has caused heavy financial hardship.



### 5.3. 'Sacrifice'<sup>40</sup> - Key Influential Factors

#### 5.3.1. *The Significance of Gender*

All the children in this study demonstrated notions of sacrifice associated with filial obligation. All indicated a responsibility to 'take care of their autistic sibling' or 'to care for them'. In the video diaries and home movies, seven children (Cases 1, 3, 4, 5, 7, 8, and 9) clearly demonstrated their daily lives as involving some form of sacrifice for their autistic siblings. For example, H1 (Case 8), despite her feelings of resentment about the changes to her life because of H2's autism, commented that sacrifice is the most important thing about being a sibling as highlighted by the following quotes:

Whenever H2 has a tantrum, he could be hungry and I always have to cook a meal and serve it to him. (video diary-4)

I am always proud of myself because I can do something for him without any complaint. I am really proud of myself but I also wish he was not autistic. I have done well for him until now and I believe I will continue to do well for him [in the future]. (video diary-5)

J1 (Case 9) also expressed an understanding that being a good sibling in his own sociocultural context involves a strong sense of sacrifice:

My brother, J2 has good and bad days. I wish to recognize his mood as fast as I can, so that I know how to deal with him well. I hope to be a good brother for J2. (video diary-5)

In particular, these quotes show that the 'sacrifice' is linked to filial obligation that differs in nature between brothers or sisters.

This study found a strong sense of obligation, among older brothers, to their autistic siblings and family. This was the case even when their parents had not emphasized

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<sup>40</sup> 'Sacrifice' is used here to indicate: 'giving up something valued (e.g. life, money, honour, benefits) for the sake of others' (see glossary). This study focuses on the strong sense of obligation to sacrifice. My interest, therefore, is to explore the influences on the individual's willingness to sacrifice, rather than the level of actual sacrifice (see section 2.5.2).

traditional filial obligations, and underlined the strength of cultural norms, expectations and duty towards disabled children. J1 explained: *'I will look after J2 in the future...'* (Case 9, reviewing session). And another participant explained: *'G2 is sick [has autism], I will be responsible for him someday.'* (G1, Case 7, aged 12, older boy sibling, video diary-1).

In Korea there is a strong sense of shame associated with the institutionalization of family members (Donnelly, 2001; Cho & Kim, 2006), and three of the nine mothers emphasized the filial responsibilities between brothers. The brothers in this study also expressed unhappiness at the idea that their autistic siblings might be institutionalized. The following exchange from a reviewing session to discuss J1's video diary offers an example:

**Interviewer:** There are many social support services for disabled people [in Seoul], such as day centres. Would you prefer to send J2 to a day centre or care for him at home?

**J1:** Well, no, I won't do that. Probably the family, our family, is more suitable for him than there, no matter how much support my brother is offered.

(Case 9, reviewing session)

In this quote, the commitment to care and 'sacrifice' are based not only on a belief that the quality of family life is better than that provided through formal services, but also a desire to attain the moral value of maintaining the autistic sibling within the family. This quote especially indicates that J1 is willing to achieve higher personal 'moral' standing of family-centred caregiving (see e.g. Kim & Theis, 2000; Kim & Lee, 2003; Lee & Farran, 2004). Under this Confucian familism value, taking care of his autistic brother is perceived his obligation.

On the other hand, the sisters of autistic children felt ambivalent, caught between conflicting personal desires and normative expectations. H1 explained how obligation towards an autistic sibling might mean that a sister or sister's spouse takes over the responsibility of caregiver after the death or incapacity of parents. However, some sisters feel a keen sense of obligation for autistic siblings that make it difficult for them

to contemplate leaving home, even after marriage. As a result, a 'caregiving' sister may be torn between caring for her autistic sibling, and caring for her husband and children. I refer to this situation as the 'sandwich obligation'<sup>41</sup> (see for example Grundy & Henretta, 2006; Sung, S.R. 2003 in relation to middle aged women and their caring responsibilities).

- Interviewer:** Do you think H2 will be a great burden to you in the future?
- H1:** He will not be a big burden. Sometimes, not often, I think caring for him could be a burden. But, it could be a big problem if I get married. It could be a great problem. How I can deal with my brother. It will be OK if Mum and Dad are still there to keep looking after him. But if Mum and Dad are dead, there are no other relatives to look after my brother. The only family members left will be just the two of us.

For me, anyway, I will only marry a man who really loves me. I will tell him, 'I cannot give up my brother when my parents die. Nobody else can care for him. He cannot be alone. So I will care for him.' Essentially, I will live with my husband in my home. Then, H2 will eventually live with us. So my husband will have contact with my brother. I will tell my husband 'I will live with my brother in our home if you want to marry me'. If he does not agree, I will say 'I cannot marry you'.

(Case 8, reviewing session)

H1's comments reveal that being the sister of an autistic child involves a strong obligation and the source of the biggest challenge in her future life. In her second comment, she struggles to reconcile her 'sacrifice' between the obligation to her autistic brother and the normative expectations of marriage associated with a Confucian, patriarchal, sociocultural context.

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<sup>41</sup> Traditional Confucian familism values in Korean provide the moral basis of family-centred caregiving. For mothers, the family is stronger as a source of obligation than as a source of support (Won & Pascall, 2004:272). Under these cultural values, mothers easily become 'sandwich carers' with caring responsibilities for both their children and their ageing parents-in-law (Kim & Lee, 2003, Jang *et al.*, 2005). In my study, I focus on sisters' dual obligations as (future) wife (daughter-in-law) and sister.

The two adolescent girls in this study both expressed concerns about the filial obligation to assume responsibility for their autistic siblings, finding this to be in tension with their own interests including marriage and employment.

**H1:** It is important to have enough money although I realize it is hard to look after H2. I wish my Mum and Dad earned more money..., I like money more than H2 (laugh). It is more important to me to earn money rather than taking care of H2.

**Interviewer:** If you have money, what do you want to do with it?

**H1:** If I have money? I would like to buy clothes, delicious food and a brand new mobile phone.

(Case 8, reviewing session)

Another example illustrates her concern about independence:

**Interviewer:** What will you do for your brother in future?

**A1:** (thinks)

**Interviewer:** Don't you think about that?

**A1:** I'll probably let him go somewhere....

**Interviewer:** Would you prefer to send him to a care-home or to look after him yourself?

**A1:** If I look after him, I won't be able to do my job.

(Case 1, aged 15, younger sister, reviewing session)

These two examples indicate that being a sister does not indicate dispensation from the normative sociocultural value of 'sacrifice' related to filial obligation. This requires women, but, at least in this study, not men, to provide practical and domestic care and help for autistic siblings. It is not surprising, therefore, that A1 and H1 hope that their autistic siblings will be able to live independently rather than be looked after by them. H1 explains her hopes:

Marriage is a possibility for H2, if he is taught well, he will be able to marry ..... Therefore, Mum and Dad and I all believe that H2 will get married and live happily for a long time.

(Case 8, video diary-12)

Overall, this study highlights ‘sacrifice’ as a central component of the self identity of siblings of autistic children and young people. Normative expectations reflect the sharp definitions and meanings of being a sibling, differentiated by gender. The ‘sacrifice’ related to filial obligation to the autistic sibling may present a big dilemma for sisters, while for brothers, the taken-for-granted cultural aspects of filial responsibility represent value, and sustain willingness to maintain their sacrifice.

### *5.3.2. The Significance of Birth Order*

Traditional Korean family values involve the ranking of children by age, with different roles assigned to older and younger siblings that encourage their distinction. This study shows how normative expectations associated with gender and birth order are disturbed by the presence of an autistic child resulting in greater responsibilities for sisters and younger brothers of autistic children.

First, the ‘sacrifice’ of older siblings’ interests or desires for the benefit of all their younger siblings or parents is highly regarded in the Korean family context and accepted without question by the older siblings. This research finds that older siblings do not perceive their ‘sacrifice’ as burdensome. Their sense of filial obligation leads to a willingness to make sacrifices for their younger siblings. For example:

Well, even if H2 was not disabled, I would be willing to look after him or give him any help he may need. To be honest, it would be unfair, if I helped him only because he was disabled. (Case8, reviewing session)

Other older siblings also said that they expect, and are willing, to take on filial obligations when their parents die. For example:

**Interviewer:** You said already [in video diary-1] that you will have to look after G2 in future?

**G1:** When mother and father are dead.

(Case 7, aged 12, older brother, reviewing session)

Only I will be responsible for my family [brother]

(Case 9, reviewing session)

These comments from older siblings illustrate that the status of the oldest child is still significant in Korean families, in terms of the roles and responsibilities ascribed. This has implications for the expectations of the older siblings of autistic children/young people, and influences the way they see themselves meeting their filial obligations in the future. Although none of the siblings in this study expressed any intention of rejecting their filial obligation it held different implications for all of them.

Second, in the context of this study, role reversal, with direct implications for 'sacrifice', often came into play when the children were younger than their autistic siblings. Younger siblings' behaviour, and their responses in this study, showed that filial obligation plays a very important part in encouraging them to demonstrate and affirm bonds with their autistic siblings. Assuming filial obligations outside the normative cultural expectations is suffused with tension and internal conflict as the conventional sibling status positions of older caregiver and younger care receiver are shifted. The younger siblings of autistic children were more reluctant to take responsibility than those who were older than their autistic siblings.

In previous section, I noted A1's (Case 1) reluctance, as a sister, to take on responsibility for the care of her older autistic sibling. But her reluctance also related to her position as a younger sibling who would not normally be expected to take responsibility for an older brother. Similarly, C1 (Case3), the youngest of three siblings with an oldest sister (C3, aged 20) and an older autistic brother (C2, aged 18) did not feel strongly obliged to take responsibility for his brother. In informal discussion with him, he said that he would like to share future care responsibilities with his older sister.

Despite the normative expectations surrounding filial obligation, gender and birth order in the Korean family tradition, some younger siblings (Cases 1, 3), and one older sibling (Case 8) had not felt obliged to take on extra responsibilities, as children, in caring for their autistic siblings. But they were aware that this responsibility would fall to them when their parents became unable to provide the necessary support.

The ambivalence surrounding felt obligation might be explained in two ways. First, regardless of the observable severity of autism, the children may not have recognized any need for intensive support or care in the future. For example, H1 (Case 8) hoped that her brother's condition would improve to the extent that he could get married. C1 (Case 3), being one of three children, hoped his elder sister would share the responsibility for the care of their autistic brother. And A1 (Case 1) who was unaware of parental plans for the future care of her brother, was concerned about her filial obligation and explicit in her wish to avoid this responsibility. Their responses may be characterized by 'hope for adequate recovery', 'expectation of shared responsibilities' in the future, and 'resistance' to filial obligation. At the time of the study, they had not seriously considered their possible future responsibilities.

An additional reason for an ambivalence of felt obligation may be knowledge of the existence of plans for the future care and accommodation of the autistic sibling (Cases 2, 4, 6). In these cases, the parents indicated that they had discussed future plans with their children and from their viewpoint, filial obligation would not involve the siblings assuming responsibility in the future. The extent to which the children, aged 7 and 8, understood the implications of these plans is not clear. Nevertheless, B1 (Case 2) and F1 (Case 6), younger siblings, and D1 (Case 4), an older sister, made no indication of denying their filial obligation.

Overall, this study illustrates that being the sibling of an autistic child involves complex patterns of 'sacrifice' that vary according to age and gender, but a felt sense of filial obligation and 'sacrifice' endures.

## **5.4. Disruptions to Normative Expectations Related to Sacrifice**

### ***5.4.1. Role Reversal and Maintaining Due Respect***

As described in Chapter 2, Korean siblings' status distinctions guide the interaction between siblings. Younger siblings are expected to show respect and obedience to older siblings while older siblings are expected to care authoritatively for, and nurture, their younger siblings. However, where siblings are younger than their autistic brother or

sister, there is a reversal of the norms regarding caregiving. In particular, three of the four younger siblings (Cases 1, 2 and 3) were positioned ambiguously within the family structure, and behaved more like older siblings. The fourth younger sibling (Case 6) was one of two sisters who were only a year apart.

**A1:** I envy my friend who has a typical [normally-developing] older brother.

**Interviewer:** Why?

**A1:** Generally, older brother would be expected to treat me kindly (laugh)....look after me.

(Case 1, reviewing session)

In Case 3, C1 (aged 13, younger brother to C2 aged 18 with autism, and C3, older sister aged 20), explained:

I feel strange because I have to help my brother now, and it is hard.

(Case 3, reviewing session)

C1's expression of '*feeling strange*' indicated that he experienced the reversal of responsibility because his older autistic brother was unable to adhere to the norms associated with being an older sibling. Nevertheless, this study finds that younger siblings are disciplined to respect their older siblings despite their autism. For instance, younger siblings were only allowed to call their older sibling by titles that traditionally show respect and deference related to birth order. So '*oppa* (older brother)' or '*onni* (older sister)' is used by younger sisters and '*hyeong* (older brother)' and '*nuna* (older sister)' by younger brothers (see section 2.5.2). Younger siblings never called their older autistic brother/sister by their names. Despite being dissatisfied with some aspects of their position living with autistic older siblings, younger siblings did not advocate a change in the traditions of respect within the family system. The expectations of respect for older siblings, including those with autism, were reinforced by parents. For instance, the following episode described by A1 (Case 1):

If my brother comes in my room or he tries to take my belongings, I shout 'get out of here' to him. Then, Mum scolds me: 'don't you talk rudely to him, be



polite [with respect]’ As a result, I have a quarrel with Mum and Dad. On occasion, I sullenly refuse to speak and go to my room. (reviewing session)

On the other hand, H1 (Case 8), older sister to her autistic brother, offered an interesting insight from an older sister’s point of view. In response to being asked:

**Interviewer:** If you were younger than H2, would it make any difference?

She responded:

**H1:** It would be more difficult. My Mum and Dad said ‘it was lucky you were older than H2, because, if you were younger than H2, you might not be paid as much attention. If H2 should be taken to somewhere, you might not understand the circumstances, so you would feel resentful’. If I was younger than him, I could not look after him so my parents could not go anywhere. If H2 was my older brother, even with autism, he should look after me. This situation would not have been good.

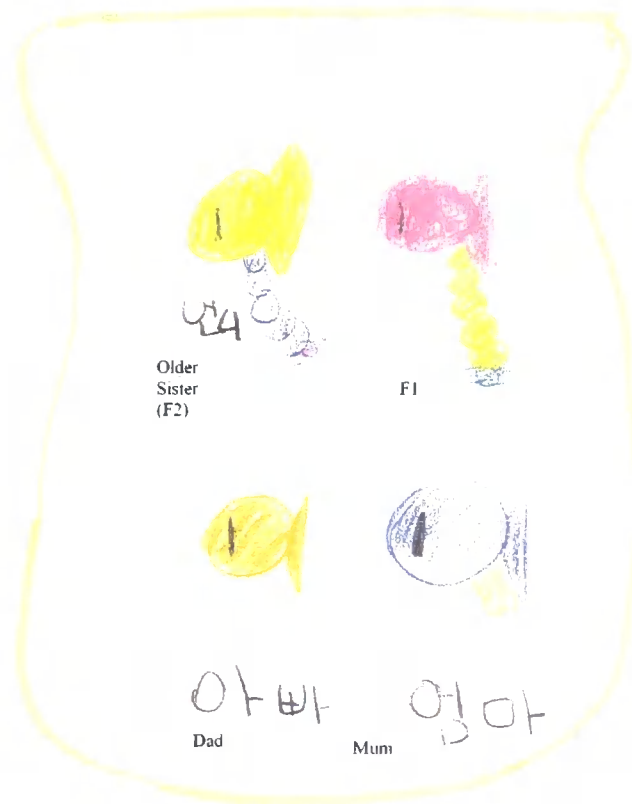
(Case 8, reviewing session)

From the position of an older sibling, H1 describes serious challenges of adjustment and dissonance between the dominant traditional family values and dilemmas of the status and role conflict experienced when a child cannot play the part expected, due to autism.

F1 (Case 6, aged 8, younger sister) perceived herself as having an ambiguous position in the family because of the continuing vulnerability of her high-functioning autistic older sister (F2, aged 9). F1 described how she was growing up with a confused status in the family system because of F2. F1 had adopted the ‘first-born’ role in part. For example, she checked on her sister from time to time during the school day (they are in different classes in the same mainstream school), brought her sister’s schoolbag to school and home, and helped her sister change clothes. In her drawing (see Figure 5-1) F1 presents herself (pink fish) behind her autistic older sister (yellow fish). In a reviewing session she explained that, for her, being behind signified ‘looking after’ or ‘taking care of’ her sister. The drawing also shows F1 and F2 above their parents

father: light brown fish, mother: blue fish) which, according to F1 indicated that the parents were taking care of both children.

**Figure 5-1** 'Fish in the net' drawing by F1 (Case 6)



However, F1 did not refer to F2 as the 'younger' and showed some resistance to the caring role by actively competing for attention with her autistic older sister. F1, as the younger sibling, called into question her adjusted status position in caring for her older autistic sister, and showed how this raised potential tensions:

- Interviewer:** F1, do you have to help your sister?  
**F1:** No  
**Interviewer:** Why?  
**F1:** I only arrange some things for her.  
**Interviewer:** What do you do?  
**F1:** My sister should look after me  
**Interviewer:** Do you think your sister should look after you?  
**F1:** [strongly] Yes.  
**Interviewer:** So you don't like [to help your sister]?

**F1:** [strongly] No. I don't like, looking after her makes me very busy.

(Case 6, reviewing session)

This quotation illustrates the contradictions inherent in F1's position as younger sister with responsibilities for her older sister.

A similar finding applied to 15 year old A1 (Case 1) who cares for her older autistic brother.

**Interviewer:** Would you feel any difference if your brother was younger than you?

**A1:** Well, ...it would be more comfortable.

**Interviewer:** What do you mean 'more comfortable'?

**A1:** I mean I could understand my circumstance because he was my younger brother. (Case 1, reviewing session)

While I cannot claim these cases as 'typical' of younger siblings' sacrifice, they do illustrate clearly the disruption to normative expectations regarding birth order and family responsibilities.

#### ***5.4.2. Disruptions to Gender related Norms***

One of the Confucianists' moral codes in Korea is that, '*Boys and girls from seven years old cannot sit together*' (Kim-Rupnow, 2001). Koreans adhere to distinct gender differences in their treatment of children from this age, and these traditional social norms guide interaction with and between boys and girls. Yet, this study found that normative gendered ideas were not followed by the families and siblings of autistic children. In particular, the normative gender boundaries were easily disrupted by the presence of the autistic child. Sisters involved in caring for their autistic brothers were unable to adhere to normative gender boundaries in the home. For example, H1 (Case 8), aged 13, shared a bedroom with her autistic younger brother:

**H1:** I have adjusted to this circumstance now. I told my friend, I

wish to have my own room. But in fact, I sleep with my brother.

**Interviewer:** Really?

**H1:** It is a secret. I am not comfortable sharing a room with him, I hope to have my own room.

(Case 8, reviewing session)

This experience for an adolescent girl is unusual and considered inappropriate in Korean society. For H1, sharing a bedroom with her autistic younger brother may represent her willingness to make sacrifices. But it is also clear that traditional gender boundaries were entirely overlooked within this family.

The home movies taken by seven and eight year old sisters of autistic children, show examples from daily life that they chose to illustrate the disruption to normative gender boundaries. In B1's (Case 2, aged 7, younger sister) home movie, I observe B2, her older autistic brother (aged 9) without clothing. B2 prefers to be without clothes and although he tolerates being dressed to go out of the house, his *modus vivendi* inside the home is to be unclothed. Moreover, D1 (aged 8) has filmed D2 (6 year-old autistic brother), in the bathroom where he is playing with water. D2's nakedness is a constant feature of life inside the family home and this image represents D2's typical and repetitive daily behaviour that is on display to D1's friends when they visit. Unusually for Korean society, D1's mother explained that she lets D1's friends' parents know about D2's condition and his behaviour in order that D1 can continue to have her friends come to the house.

Despite the understanding shown by family members and friends, it is important to remember that in Korean society such exposure to nakedness is considered shameful and humiliating for both the naked person and the observer (Kim, T.Y., 2003; Im *et al.*, 2004). From the reviewing sessions with two sisters, B1 and D1, it was clear that they were 'embarrassed' by their brothers' nakedness:

**Interviewer:** Are you all right while your brother is without any clothes?

**B1:** I am so embarrassed. (Case 2, reviewing session)

- Interviewer:** Does D2 play in the bathroom without clothes everyday?  
**D1:** [yes]  
**Interviewer:** Are you all right if you see him?  
**D1:** Embarrassed. (Case 4, reviewing session)

An adolescent sister (A1, Case 1, aged 15) of an adolescent autistic brother, felt particularly embarrassed:

- Interviewer:** Would you feel any difference if your brother was a sister?  
**A1:** It would be more comfortable if he was a sister  
**Interviewer:** Why?  
**A1:** Because we are girls  
**Interviewer:** Girls, what do you mean 'comfortable'?  
**A1:** He...being naked.  
**Interviewer:** Did he go around without clothes at home?  
**A1:** Yes, at that time.  
**Interviewer:** At the time?  
**A1:** Yes. Seeing him [naked] is really embarrassing. He is now a big boy. (Case 1, reviewing session)

Discussion of bodies and bodily experiences is still generally taboo in Korea, particularly between men and women (see Shim, 2001), and as an older male researcher I was not able to explore with these sisters the impact of their brothers' 'nakedness'. However, I argue that the cultural barriers to discussing nakedness led to the silencing of the sisters' views and repression of their feelings. The invisibility of their difficulties, linked to caring responsibilities that compromised gender boundaries, had significant consequences for these sisters (Cases 1, 4 and 8) who showed some ambiguity in their identities as they took on some of the normative expectations of mothers (see Min, P.G., 2001; Kim, J.S., 2001) and crossed the normative boundaries of sister-brother relationships.

For brothers of autistic children, gender was only weakly related to notions of 'sacrifice' because the roles of brothers were limited to accompanying, or playing with their autistic siblings rather than taking responsibility for providing practical resources (as we shall see in section 5.5.1). Cases 5, 7 and 9, involve older boys with younger autistic

brothers. The evidence of this study suggests that the filial obligation associated with the role of older brother was simply reinforced by the presence of younger autistic siblings. The strength of filial responsibility formed part of the normative order as the following quotation illustrates:

[I look after J2] because he is my brother and he needs my help.

(Case 9, reviewing session)

Having discussed the implications of birth order and gender on the lives of siblings of autistic children, I now go on to examine the roles of siblings as caregivers.

## 5.5. The Enduring Nature of ‘Sacrifice’

### 5.5.1. *Siblings as Caregivers*<sup>42</sup>.

In this study, and consistent with the Confucian ideology of ‘good siblings’ the sisters and brothers of autistic children were a key source of support within the family.

Although the sisters and brothers in this study did not directly take on parental caring roles for their autistic siblings, their roles were more consistent with the identity of ‘carer’ ‘minder’ or ‘protector’ than ‘receiver’ of nurturing, support and guidance. All the sisters in this study took responsibility for caregiving tasks arising from their autistic siblings’ needs. These included: acting as playmate (when they would prefer to play with their own friends), providing supervision, and helping with daily activities such as washing, feeding and changing clothes. For example, H1 (Case 8) described how she must be present for her brother to go to sleep:

He could not sleep without me. For example, I have to go to bed late because of studying. I study in the living room because H2 must sleep in our room. But he

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<sup>42</sup> Although this study does not measure the level and frequency of children’s caregiving activities, 64 of 110 home movie entries involved the children caring for or supporting their autistic siblings. And 44 of the 77 video diary entries included references to caring or supporting activities such as cooking (A1, D1, H1), shopping (D1, H1, J1), personal care (help going to bed (C1), dressing (B1), bathing (H1), giving medicine (C1), ensuring safety (all cases), looking after while parents are out of the home (all cases), interpreting (H1), and responding to sibling distress (all cases).

cannot sleep by himself. So, I stop studying and lie down beside H2 until he goes to sleep. Then H2 can sleep well. (Case 8, Reviewing session)

Here we see H1 giving up her studying and devoting important time to her younger autistic sibling, without attempting to pass the responsibility to her parents.

Other examples include two older sisters helping their autistic siblings, even though their parents were with them. D1 (Case 4) often carried out domestic caretaking tasks at night including preparation of food and helping her brother to eat.

H1 (Case 8) accompanied her autistic brother to the shop to buy food (Figure 5-2). The home movies, video diaries and reviewing sessions indicated that while not time consuming in comparison with parents' caring activities, these were tasks carried out on a daily basis. Despite this, none of the sisters identified themselves as 'carers'.

**Figure 5-2** Shopping with Autistic Sibling (Case 8, home movie-2, time lap 42:23)



On the other hand, none of the brothers of autistic children in this study were likely to do domestic caregiving tasks, although they did so if their parents were not present. All brothers' caregiving focused on supervising their autistic siblings, for example, keeping an eye, or playing, while their parents were out. J1 (Case 9) produced his movie while he was on an outing to a mountain with his autistic brother at a weekend (Figure 5-3). The movie shows him following his autistic brother.

**Figure 5-3** Outing with Autistic Sibling (Case 9, home movie-11, time lap 36:57)



Another example is offered by C1 (Case 3) who filmed his older autistic brother C2 while they were playing badminton at home (Figure 5-4). In the reviewing session C1 used this image to explain that C2 refused to play outside and stayed at home after school. His typical behaviours were looking at the newspaper, playing badminton and bouncing a ball repetitively. C1's parents gave him the responsibility of playing with C2 at home, but his engagement with C2 indicated a supervisory rather than direct caring role.

**Figure 5-4** Playing with Autistic Sibling (Case 3, home movie-8, time lap 00:05)<sup>43</sup>



<sup>43</sup> The quality of this home movie was not good due to low light capacity of PMP.



This focus on supervisory, rather than practical tasks is further illustrated by an image (Figure 5-5) and accompanying sound track from J1's home movie.

**Figure 5-5** Eating Pear (Case 9, home movie-5, time lap 15:15)



Today, J2 said 'bae' (pear) to me. I did not know what he said. I realized he wanted me to peel a pear. I have never peeled a pear before. But I peeled the pear for J2 today and he was happy. (Case 9, home movie-5)

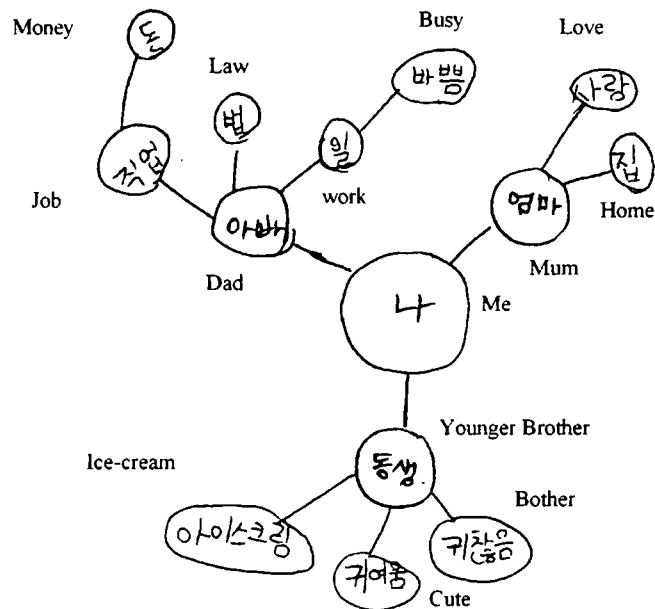
*'I have never peeled a pear before'* reflects traditional gendered work distinctions. Discussing the home movie in a reviewing session J1 suggested that women's roles should be to be the carers for offspring within the family, which led to the following exchange:

- Interviewer:** Well, I see. If you have girl friend or want to get married, but she is not willing to live together with your brother.....
- J1:** I would never marry that kind of girl.
- Interviewer:** What do you mean?
- J1:** I will marry a woman who is generously willing to look after my brother

(Case 9, reviewing Session)

This sentence demonstrates the filial responsibility of a son being extended to his partner in the future, consistent with Confucian norms (see Kim, J.S., 2001). J1 depicted distinctive roles of mother and father through socio-cultural values in the following spider web (Figure 5-6). His father's role was predominantly described in terms associated with a traditional breadwinner model (job, money, work, busy), while the mother was described with the words 'home' and 'love'.

Figure 5-6 Spider-Web 'People in My Family' (Case 9)



This spider web drawing suggests that, in the eyes of J1, the traditional Korean cultural heritage, in which women are responsible for all household tasks, and men responsible for work outside the home, is still alive.

The two adolescent sisters in the study, A1 and H1 (Cases 1 and 8) offered different views of their future responsibilities. For A1, caring for her older brother A2, implied a direct sacrifice: *'If I look after him, I could not do anything'* (A1, reviewing session). H1 on the other hand indicated that: *'I will live together to look after my brother'* (H1, reviewing session). Whether reluctant or willing to care for their brothers in the future, both A1 and H1 were likely to be responsible for the majority of personal care tasks related to caregiving.

Although caring for their autistic brothers and sisters was not described as a primary role by the siblings in this study, it is indisputably a central part of 'being a good sibling' in Korea. Furthermore, the siblings indicated that they have always assumed that they will (willingly or less willingly) have to take over the caregivers' role as a 'substitute parent' in the future.

### ***5.5.2. Siblings as a Financial Resource***

The six oldest siblings in this study all indicated that financial considerations had a large impact on the experience of living with an autistic brother or sister. All the families in this study have struggled with financial hardship because of high levels of spending on special education, therapies or medical treatments for their autistic children. This has had a direct effect on the lives of the child participants. For instance, H1 (Case 8), aged 13, commented:

'Honestly it's only money and money alone cannot bring happiness. Nevertheless, people say 'money is the best'. I agree. Money is not all things but I think money and happiness are the most important elements in the current world. I cannot do whatever I want to do without money. Also, I cannot live without happiness. Therefore, I envy people who have money and happiness. ....Our family lives with happiness. I now need money as well. To be honest, I do not blame all the family's problems on H2 but his needs are the cause of most of the money problems. (Case 8, video diary-11)

The responses of the two adolescent sisters, H1 and A1, (Cases 8 and 1) to questions of financial hardship, reflected different expectations of sons and daughters. When discussing future employment, they indicated that gaining a job that they liked would be more important than gaining a job that would enable them to support their autistic siblings financially. H1 commented:

To be honest, I would like to look for a job that I will like to do, even if it does not mean a well paid career. (Case 8, reviewing session)

From this comment it seems reasonable to conclude that providing financially for her autistic sibling was not a major sacrifice she expected to make. Consistent with normative expectations related to filial piety, this was a greater imperative for boys than girls.

All the brothers in this study were willing to sacrifice themselves to assist the family financially and eventually to take over financial responsibility for the needs of their autistic siblings. In a reviewing session with J1 for instance, it became clear that he wanted to become a lawyer to earn more money, although his family could already be classified as a high-income family:

- Interviewer:** What would you do if you earned more money?  
**J1:** It's so I can look after J2..... .Dad is a judge but he has no money.  
**Interviewer:** Your dad is a public official  
**J1:** That's why, but I hope to earn more money  
**Interviewer:** Why do you think you should earn more money?  
**J1:** In order to look after J2  
**Interviewer:** Why?  
**J1:** In order to look after J2, I need to hire a 'pachulbu' [housework assistant] for him

(Case 9, reviewing session)

J1 explained that getting a good job is very important so that he can give financial assistance to his family and autistic sibling in later life. Getting a high salaried job would be a means of offering secure and on-going care and support for his autistic brother. Two siblings, an adolescent girl and a boy (Cases 1 and 7) expressed a wish to become a special education teacher and a social worker respectively, careers related to their experiences of living with an autistic sibling.

These findings suggest that siblings have different expectations regarding their future roles and responsibilities towards their autistic siblings. Sisters recognized that there would be financial issues regarding the support of the sibling in later life, but they did

not expect and were not expected to sacrifice themselves for the financial benefit of other family members.

### 5.5.3. Academic and Social Success as a Route to Social Security

Educational achievement is regarded as the best route to social success in Korea (Lee, W.S., 2004). Academic study was a recurring theme among the siblings who spent six days a week in school followed by further study at school or a private educational institute (*'hakwon'*). J1 (Case 9) described his academic workload in video diary-9:

I also have to do lots of school work. I have to prepare for exams and do English homework from the English *hakwon*.....It is very hard work preparing for exams now. I always go to bed around 12:00 or 1:00. Time goes too fast by the time I have packed my school bag and have done my homework. Moreover, I am really busy now preparing for final-term exam. So I go to bed very late. So I am really tired.

(Case 9, video diary-9)

Reviewing sessions with J1 and H1 showed their own awareness of the importance of academic success in achieving and maintaining higher socioeconomic status in Korea. But all siblings in this study worked hard to fulfil parental expectations of high academic achievement. In the reviewing session with J1 he explained:

- Interviewer:** You said that you should study very hard. Why?
- J1:** Yes, my mum and dad said 'you should study hard because we could not expect your brother to'
- Interviewer:** Did you feel that this was a burden?
- J1:** I did not feel this was a burden, rather, I will do my best.
- Interviewer:** What do you mean?
- J1:** J2 could not be expected to do well at his studies, I will have to earn money.

(Case 9, reviewing session )

J1 understood that his parents expected him to achieve academically, in part to compensate for his autistic brother's limitations, and also in order to fulfil future financial obligations to care for J2. Although J1 did not describe studying as a burden, the weight of expectation can be identified as a form of sacrifice to meet parental expectations.

Another illustration is offered by the following conversation between A1 (Case 1) and her parents:

- Father:** My A1 is studying very hard....
- Mother:** Which university do you want to go?
- A1:** Special education
- Father:** hmm, of course
- A1:** D university.
- Mother:** Why D university?
- A1:** (laughing)
- Mother:** You should admit to E or D university.
- A1:** How I can admit to E university?
- Mother:** Why can't you?
- A1:** I can't
- Father:** Don't lose confidence.
- Mother:** You should work a bit more
- Father:** Yes
- Mother:** You got the first Mark
- Father:** I believe you can do well
- Mother:** You got the first. Why can't you go to E university?
- A1:** hmm
- Mother:** You can be admitted [to a good university]

(Case 1, Home movie-3)

A1's parents had high expectations of higher level educational achievements for her. Although A1 was conscious of these strong parental expectations, she focused her studies in order to accomplish her own goals (to be a special education teacher) as well as to meet her parents' strong demands (Figure 5-7).

**Figure 5-7** Studying at Late Night (Case 1, home movie-3, time lap 0:00:03)



## 5.6. Parents' Views

Parents' perspectives overall were not dissimilar from the accounts of their normally developing children. Most parents considered that good siblings were required to make 'sacrifices' for the sake of their autistic sibling and their parents. However, in contrast to their childrens' accounts, parents in eight of the nine cases wished that their normally developing children did not have to make a life-long sacrifice associated with the filial obligation towards their autistic siblings. However they saw no alternative.

Although filial piety within Confucian family codes was not directly imposed by parents, they still expected their normally developing children to show strong willingness to take responsibility for their autistic siblings. In an interview with J1's (Case 9) mother, she commented:

He told me about caretaking. We never said 'you should take care of J2', because he might feel this as a burden. So, as Mum and Dad, we will care for J2 continually, although we don't know what is going to happen in the future. We never asked what he feels he has to do. Although we never said 'you should take on the role', he might feel a deep sense of obligation. So he said 'My [future]

wife and I will have to earn plenty of money so that we can pay for a paid-caregiver for J2. Therefore, I can take care of him'... Then we realized he felt his brother was a really big burden. For me, I appreciate his willingness to accept this obligation

Although parents in eight of the nine cases did not wish to enforce such 'sacrifice' for autistic children on their normally developing children, they realized that siblings might accept their filial obligation for their autistic brothers and sisters. All the parents in this study acknowledged with gratitude that their normally developing children would accept this on-going sacrifice. H1's mother, for example, also had a disabled older brother. She is still supporting her brother who is in a residential care home. H1's mother did not want to impose a serious obligation on H1, but she did hope that H1 would be willing to make sacrifices for her brother.

Moreover, all parents agreed that filial obligation has different implications according to the birth order and gender. However, in line with the Confucian familism code, parents saw no contradiction in a younger sibling taking on an older sibling's responsibilities and did not acknowledge that this represented a disruption of the normative expectations relating to birth order, gender and family responsibilities.

In terms of gender, the parents of the girls did not recognize the inherent tensions associated with their daughters' experiences in sharing bedrooms or responding to their autistic brothers' displays of nakedness. For example, A1's (Case 1) mother said:

Even though her brother was totally naked, she was not concerned, she said 'brother, put your clothes on'. She accepts this as a natural part of their daily lives.

In this sense, parents focused on the adjustment between siblings rather than the problem behaviours of the autistic child and the impact this might have on normative expectations in relation to gender. It seems that sisters were regarded as good siblings where they had adopted a quasi parental role and there was little expressed concern about the implications of their caring role on their developing gender identity.



Nevertheless, parents differed in their views of their normally developing children as caregivers. Interviews with the mothers indicated that they felt that caring for the autistic child was primarily their own responsibility. But they still admitted over indulging their normally developing children to compensate them for their contributions in caring for their autistic siblings. Normally developing children were asked to be more mature, independent, successful and achieve more to compensate for the limitations of their autistic siblings. As J1's (Case 9) mother said:

And due to J2, I expect more of him [J1]. It is true I tend to over indulge him [to compensate for J2]

Overall, through the eyes of the parents, being the sibling of an autistic child meant accepting increased levels of sacrifice. Taking on filial obligations was perceived to be a challenging experience. More mature, tolerant and responsible attitudes towards parents and autistic siblings were described as 'good' qualities of the children who exceeded parental expectations for their age. In reality, parents expected that their normally developing children's sacrifice would be extended under the ideology of filial obligation, although they did not consciously wish to impose such sacrifice on the siblings of their autistic children.

## 5.7. Summary

The overall picture painted by the children is one of 'sacrifice related to filial obligation' for the present and future well-being of their autistic siblings. Responsibility of children for their disabled siblings is already a preoccupation of much literature (see chapter 2). But this chapter has demonstrated that sibling obligations are strongly upheld by values of Confucian familism such as 'filial piety'. Birth order and gender are also critical variables in determining the day to day realities of filial responsibility, although these may be applied flexibly where the disability of one child leads to a disruption of normative expectations.

The children were generally willing to make sacrifices for their autistic siblings as well as for their families. In the case of the three older brothers, the added responsibilities gave them a strong positive sense of 'filial duty'. Although the one younger brother and five sisters did accept responsibilities that went beyond normative cultural expectations they were aware that unusual responsibilities were being placed on them. And their expressions of reluctance reflected the tensions that characterized disruptions to normative cultural expectations that place responsibility firmly with older brothers.

Where the sibling was younger than the autistic brother or sister, the expected roles and responsibilities were reversed. But traditional cultural expectations were strongly enforced to maintain the respect that younger siblings are expected to show older siblings. On the other hand, the normative expectations associated with gender (sons taking responsibility for their sisters, and strictly gendered behaviour boundaries) were apparently dispensable so that both older and younger sisters were expected to accept quasi parental roles. Moreover, these altered expectations had strong implications for the ongoing responsibilities of the younger brother and the sisters. They foresaw their current roles continuing into the future and adulthood, with the expectation of care giving (themselves or through partners) and providing sufficient financial means for the necessary care of their autistic siblings.

Parents' (nine mothers and two fathers) understandings of the role of their normally developing children were conveyed through interviews. These suggested that nine of the eleven parents, including the one father, did not wish their normally developing children to take responsibility for their autistic sibling. Nevertheless, they had strong expectations of their normally developing children's roles and responsibilities.

Taking on filial obligations was an expectation consistent with the notion of being a 'good' sibling. But parents rejected the identity of 'substitute carer' for their normally developing children. The data suggest that being a sibling of an autistic child strengthens existing, and imposes new, forms of filial obligation that involve giving greater priority to the welfare and interests of their autistic siblings than to their own personal desires or needs. But I also argue that the siblings of autistic children should

not be regarded as making these sacrifices entirely willingly. In their everyday lives, they learned that these obligations were 'not avoidable'.

In the following chapter, I present further findings and analysis that focus on the ways in which siblings portray their autistic siblings and their sibling relationships.

## **Chapter Six**

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# **Same but Different: Children's Experiences, Perceptions and Understandings of Their Autistic Siblings**

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## 6.1. Introduction

In this chapter, I focus on children's experiences and understandings of their autistic siblings, and their sibling relationships within the Korean sociocultural context. Section 6.2 shows how the children perceive and understand their autistic siblings. Section 6.3 explores the 'same but different' nature of sibling relationships in everyday life, while section 6.4 explores Korean cultural understandings of sibling relationships that are revealed in two sub-themes: *Jeong* (strong interpersonal ties) and *Woori* (togetherness). In the final section, 6.5, I present the parents' understandings and expectations of their normally developing children's experiences and relationships with their autistic siblings.

## 6.2. Children's Perceptions of Their Autistic Siblings

### 6.2.1. Changes in the Children's Perceptions

In my study, the children describe their autistic siblings in the 'here and now' as well as on the basis of their earlier experiences. Siblings' views of their autistic siblings are not fixed. Changing views and understandings are regarded as part of the everyday lives of the siblings in my sample. These changes are closely linked to their developmental stages. Regardless of gender, the older children (Cases 4, 5, 7, 8 and 9) all had positive perceptions of their autistic younger siblings. On reaching adolescence the older siblings (Cases 5, 7, 8, and 9) described important changes in their perceptions over years of living in close proximity with their autistic younger sibling, invariably becoming more positive over time. For example, H1 (Case 8, aged 13, older sister) described significant changes in her views, feelings and ways of reacting to her autistic younger brother.

So I definitely think that my views towards my brother are different compared to how I was before. If I take every individual aspect separately I realize he has changed. But I guess I get used to his behaviours and I don't notice the changes as much, because I think: was he was always like that? ..... But I feel that my

brother indeed has changed a lot. I am fascinated if my brother is doing new things, even it is small things.

(Case 8, reviewing session)

H1 experienced a process of change as she grew older, adapting and increasing her ability to 'cope' with her autistic younger brother. She spent a lot of time with him each day and was proud of her ability to cope well with the challenging behaviours associated with autism.

J1 (Case 9, aged 13, older brother) also described the effect on his life of having an autistic younger brother, and how his perceptions have changed over time.

I felt it was difficult to be with him in the past, but I think it was a short time.

Now, he is not problem to me at all. (Case 9, home movie-5)

J1 developed a more positive understanding of autism through a lifetime of shared experiences with his autistic brother. His positive attitude increased as did his ability to cope with the challenges presented by living with an autistic sibling, such as disturbed sleep patterns and lack of privacy.

H1 and J1's comments suggest that they have adapted to life with an autistic younger sibling through increased understanding of autism and acceptance of daily caring responsibilities. But the picture looks rather different for younger children (Cases 1, 2, 3, and 6) whose autistic siblings are older than them. Although they were aware of their older siblings' disability (e.g. Hames, 1998; 2007), they held ambivalent feelings, even when they reached adolescence (Cases 1 and 3). For example, A1 (Case 1, aged 15) explained how, despite being used to her older brother's behaviour, she still felt threatened by him sometimes.

**Interviewer:** If you think about the past, do you think you have changed your view of your older brother?

**A1:** I got used to him. I don't mind him anymore now.  
[qualifies] I do not mean I'm going to give up on him.

(Case 1, reviewing session)

My brother and dad were playing on the game console when I finished ‘*Yaja*’ [extra study in school at night]. Yesterday, I didn’t like him much, but now, I am not angry or anything when I see him, even though I was a little annoyed earlier. I watched TV in my room..... Now I am feeling OK. (Case 1, video diary-1)

A1 has adjusted to her brother’s typical behaviours (including disruption, aggression, violence and nudity), and filters her views of him through a lens of ‘*ups and downs*’<sup>44</sup> (Connors & Stalker, 2003:84). A1 perceives her older brother as having little or no control and when faced with his challenging behaviour she withdraws to regain equilibrium.

C1 (Case 3, aged 13) characterized C2, his autistic older brother, as ‘abnormal’ meaning that he is autistic. In the video diary, C1 reflected on C2’s typical behaviours:

When I work and play on the game console, my older brother comes home, and as soon as he comes in the room, he gets changed and locks the door, and reads his newspaper. If I need anything from the room I can’t get it because he locks the door. And when I’m desperate for the toilet he also locks the toilet door, even though he doesn’t do anything in there. He locks the door always. Some while ago he used to lock the front door also. I really don’t like that about him. Because he locks the door it is inconvenient and I don’t like having to unlock the door every time. I wish he wouldn’t lock the doors. (Case 3, Video diary-6)

**Interviewer:** What do you do if he locks the door?

**C1:** I normally ask him to come out. But....of course he sometimes does not come out. Sometimes, I open the door with key and ask him to come out. Then, he comes out.

(Case 3, reviewing session)

These two examples suggest that, as these younger siblings reach adolescence, they have managed to integrate the consequences of their siblings’ autism. But they still experience some difficulties in understanding their older autistic siblings’ behaviours. The views of the four children who were younger than their autistic siblings, in

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<sup>44</sup> This term was used by Connors and Stalker to refer to siblings who generally got on well with their disabled brother or sister, but had problems at times.

particular those who are younger in age (e.g. B1, aged 7, Case 2, and F1, aged 8, Case 6) focused on continuing difficulties in adjusting to their older autistic siblings' behaviours, a situation that may be related to the norms of respect and compliance that younger siblings are expected to show their older siblings.

### *6.2.2. Significant Change in Autism*

Changing views and experiences of children were also strongly linked to changes in the manifestations of their siblings' autism. Improvements in sociability and communication marked important changes by four children (Cases 3, 5, 8, and 9). For example, J1 (Case 9) described his brother as 'getting better':

**Interviewer:** You told me J2 was getting better. What do you mean?

**J1:** Every day is a routine of going to school, then to lessons, then going out to socialize, I think slowly his listening is getting better. He can talk better now. Before he couldn't say what he really meant all the time but now he can finish what he is saying by using full sentences.

**Interviewer:** Do you mean you can communicate with him?

**J1:** Yes, He can understand me. For example he answers my questions and he now tells me what he wants to eat and he completes his sentences.

(Case 9, reviewing session)

Whenever I study, J2 also studies. He has lots of homework such as spelling. Last time, he got the top mark for singing the national anthem. He always gets perfect marks for the spelling test. He is working very hard. He is working with Mum all day when he prepares for the spelling test. .... It is not easy for him. He is working hard all day. He gets perfect marks. I think he is getting better year by year. ....I think he could recover from autism. He could be a normal person. I wish he would recover from autism. (Case 9, video diary-8)

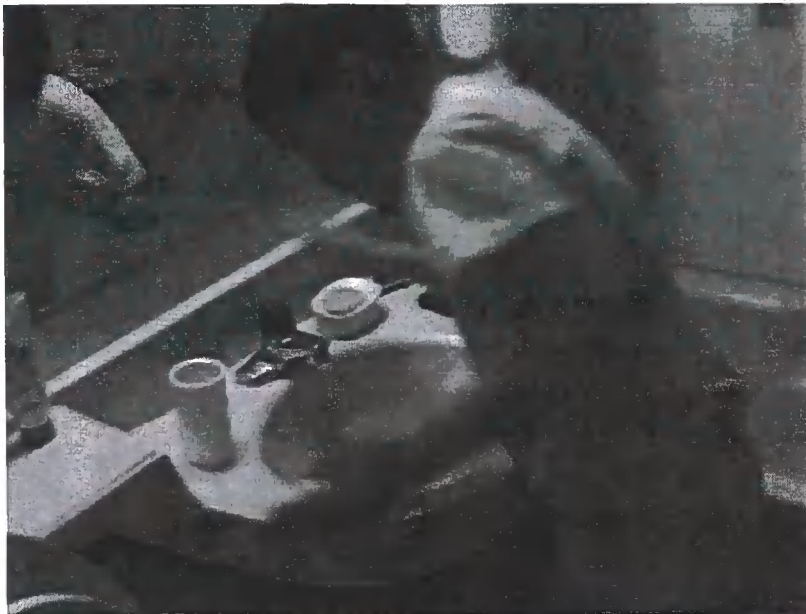
The changes in conditions of autistic siblings included improvement in academic abilities, improved communication, and undertaking more joint activities. Through observing the developmental stage and abilities of his autistic brother, J1 learned how



his autistic younger brother's fragility and unpredictability were minimized. J1 stated that he hoped for his brother to be free of autism. Improvements in communication led to greater capacity in autistic children's capacity to follow their siblings' verbal instructions as illustrated in Figures 6-1 and 6-2 and in H1's comment about a scene in her home movie:

I let him move the mouse on purpose. I wanted to show you that he could follow my directions. (Case 8, reviewing session)

**Figure 6-1** J2 washing & brushing teeth under direction of J1  
(Case 9, home movie-9, time laps 24:47, 24:54)



**Figure 6-2** H2 preparing bed under direction of H1 (Case 8, home movie-6, time lap 26:44)



These changes in communicative capacity had strong meaning for the siblings, reflected in their views and attitudes towards, and behaviours with, their autistic siblings.

In contrast, children developed negative perceptions of their autistic siblings as a result of behaviours that did not follow expected patterns and involved a lack of cooperation. This was the case for all the sisters (Cases 1, 2, 4, 6, 8) and one younger brother (Case 3). Their views were significantly affected by an inability to understand behavioural changes in their autistic siblings. For example, in a reviewing session, C1 (Case 3) described notable changes in his autistic older brother (C2, aged 18):

My brother used to go out by himself from 6 until 10. He went to the playground and played with a ball sometimes by himself, and some times with me and Dad. The three of us liked going to the baseball match. But, one day he suddenly didn't want to come out with me and Dad to play football. He didn't want to go out anymore. We play badminton now because he doesn't want to go out, so we play badminton in the house. ....

My friends asked to play outside while Mum was away from home but my brother was at home. Mum did not allow me to go out with friends because she told me 'your brother shouldn't stay alone at home'.

(Case 3, reviewing session)

Here, C1 is describing the strain associated with the change in C2's habits and behaviour. These have a direct impact on C1's daily life as his mother expects that he will respond to C2's changes in behaviour by changing his own pattern of tending to his brother.

A1 and H1, adolescent sisters (Cases 1 and 8) described how they had difficulty predicting their autistic siblings' behaviours:

... when H2 has tantrums for no obvious reason, I guess he might be very hungry. But even so I would only know if he tells me that he is hungry. Then I would do something for him. I would like it if he could tell me that he is hungry one day. Sometimes, it is really difficult honestly, when his mood changes for no obvious reasons.

(Case 8, video diary-4)

My brother scribbled on my maths text book. I am used to these happenings all the time, but I felt so upset. I locked the door, didn't watch TV and I stayed in my room, crying and clenching pieces of tissue.

(Case 1, video diary-1)

Even though H1 and A1 have become accustomed to the unpredictable behaviours of their autistic brothers, their views still focused on the unpredictability and uncertainty associated with autism. Erratic behaviours were confusing and difficult for them to understand and made them wary of being around their autistic siblings.

To sum up, the children's perceptions of their autistic siblings change over time: i) as they grow and mature themselves, and ii) in response to changing symptoms and behaviours of their autistic sibling. But such changes were an integral part of everyday life, and the children did not perceive their siblings primarily as being 'autistic'. For instance, H1 commented:

H2 is '*jangea*' [an autistic] child. That is true, but I don't think he really looks any different to me.

(Case 8, video diary 2)

Their perceptions of their siblings also strongly influenced their sibling relationships, which I address in the following section.

### **6.3. The Children's Perceptions of Sibling Relationships**

Children's perceptions of their sibling relationships were communicated through the children's video diaries and home movies as well as in reviewing sessions. A strong theme running through the data was that of 'sameness'. Interestingly, 'difference' was perceived principally in terms of the characteristics of their autistic sibling and NOT in terms of their relationships. For this reason I have chosen to present the findings relating to 'sameness' first.

#### **6.3.1. Sameness**

Despite children's awareness of their siblings' autism that makes coping with, or managing, their autistic brother or sister difficult, eight of nine children (Cases 1, 3, 4, 5, 6, 7, 8, and 9) conceptualized their relationships with their autistic sibling as being 'the same' as those of other siblings

First, the home movies and video diaries showed that daily joint activities (e.g. playing, shopping, eating and outings) are perceived by siblings as part of their normal relationships with their autistic brother or sister, even though they encountered some difficulties in a range of activities. For instance, D1 (Case 4, older sister) undertook many daily activities with her autistic younger brother. Although her brother's autism presented significant barriers to shared activities, D1 wanted to show me that she could undertake joint activities with her autistic brother.

The three siblings in middle or high school (Case 1, 8 and 9) found it harder to share leisure activities together because of the length of the school day and time devoted to '*hakwon*' (private education institute attended 'after school'). For example, A1 (Case 1, aged 15, younger sister) did not depict any joint activities with her autistic older brother

in her videos. In the video diary, however, she talked of her wish to do activities together with her autistic older brother:

Now I'm in high school I don't have much time for my family. I feel a little disappointed in myself. While I was in Secondary school my brother and Dad used to go the mountains but I didn't want to go at that time. Now, I would like to go but I just don't have time to. Today, without me, the whole family has gone to DO-HO-BU-CHUNG-SA. (Case 1, video diary-4)

Crucially, the quality of 'sameness' in children's descriptions of their relationships with their autistic siblings was linked to engaging in typical daily activities with them. And it is precisely through engaging in joint activities that sibling relationships can be improved and enhanced (e.g. Knott *et al.*, 2007).

Second, despite clear challenges in communicating with their autistic siblings (i.e. understanding their verbal or nonverbal expressions), the children in this study focused on their ability to communicate as part of what defined their relationships with their autistic siblings in terms of 'sameness'. Indeed, they were proud of their abilities in communicating with their autistic siblings. For example, in the reviewing session after viewing H1's home movies, H1 conveyed how she was able to understand and interpret her autistic brother's verbal language:

**Interviewer:** Do you think you can communicate with H2 now?

**H1:** Yes, 100% I am sure. But sometimes I cannot hear him speaking. It's because he doesn't want to speak. He does it purposely. But I could understand 100%. For example, when I ask him to put things in the bin, he does it, and just earlier [when we watched the home movie] you see I asked him to turn the speaker off, and he did..... So, I am an interpreter in my house. When we have visitors, most people don't understand what he is saying, so I interpret for them. When we visit my Grandfather I think he is getting used to my brother's accent. He is starting to pick up what he is saying.

**Interviewer:** Oh, I see.

- H1:** I think I'm proud of myself. No one else can understand what my brother is saying, only I can understand. Honestly, I think my Dad is the worst person and then Mum doesn't understand straight away if H2 speaks a new word. However, I am the best person to understand straight away whenever he uses new words.
- Interviewer:** Are you?
- H1:** Yes I am. I can recognize H2's pronunciation.
- Interviewer:** Why do you think that you can?
- H1:** Mum says that it's because we are siblings we must have some sort of connection. But I think I am a little bit more advanced in understanding his pronunciation.

(Case 8, reviewing session)

H1's explanation indicates that communication with her autistic brother goes beyond understanding words and phrases and embraces other forms of communication.

The children also stressed that the deficits in their autistic siblings' comprehension did not present an obstacle to communication between them. For example, H1 (Case 8) commenting on her movie of a visit to the shop, talked about how she instructed her brother to take care in crossing the road and not to pick things up in the shop:

I deliberately told him to do those things. I wanted to show you that he can understand whatever I say to him.

(Case 8, reviewing session)

And J1 (Case 9) commenting on his brother's progress in becoming more sociable, expressed his pride in the level of communication he had achieved:

My brother J2 can understand more of what I say than others.

(Case 9, video diary-2)

These comments suggest that the siblings of autistic children develop specialized communication skills and although these become part of everyday life, their focus remains on their ability to communicate effectively, and NOT on the different forms of

communication required in interacting with their autistic siblings. Put another way, it is the lack of reciprocal communication that may present a significant barrier to the development and maintenance of satisfying relationships between siblings and their autistic brothers and sisters (Kaminsky & Dewey, 2001).

Third, regardless of the hardships associated with having an autistic sibling, the children in this study value their siblings highly. For example, two adolescent siblings (Case 8, and 9) said that their relationships were better than others who have normally developing brothers or sisters. H1 commented that her relationship with her autistic younger brother was less competitive and quarrelsome than that of typically developing siblings:

There are many advantages in my relationship with H2. Most of all, we do not fight each other. If both siblings were normally developing children, they would fight and quarrel with each other because of food, or small things. But we don't.....  
(Case 8, video diary-7)

Further evidence suggested that the normative expectations associated with sibling relationships in Korea can also be achieved among children with autistic siblings. These relationships involve older siblings having affection for, whilst also protecting and having authority over, younger siblings. All younger siblings are expected to respect and obey their older siblings. For instance, J1 (Case 9) described respect, obedience and cooperation as crucial aspects of his own sibling relationship with J2.

My brother J2, he might more obey me more than others.  
(Case 9, video diary-2).

There used to be embarrassing moments because of J2. There are none now, and he is my cute brother. I'm just proud to have a brother like J2. I am so happy to have a brother like J2. Recently he has been good, and he is not having so many tantrums and is improving. Also he listens to what we say so he does not affect my life style at all. If he was a normal child he might have not listened at all, but J2 is far better than other brothers because he always listens.

(Case 9, video diary-4)

- Interviewer:** Have you not compared, or were you not envious of, other friends siblings?
- J1:** I used to envy them when they played with their siblings  
but now I think this is better
- Interviewer:** Why?
- J1:** Because he listens and obeys me better.  
And, normally between brothers, they don't think their younger brothers are cute. But even though I see my brother everyday, I like him. (Case 9, reviewing session)

Here J1 stresses the importance of the norms of sibling relationships in which the older sibling has authority over and shows affection towards the younger.

One older sibling (G1, Case 7, older brother) went as far as explaining that, as the older brother, he is allowed to physically discipline his autistic younger brother:

I will not hit him again. I hit my brother because he scribbles and rips all my stuff and he hit me. But it's G2's fault. So, I hit him. From now on I will try to treat my brother kindly and to understand him better. (Case 7, video diary-3)

My Mum lets me discipline him, when he has done wrong to me.  
(Case 7, reviewing session)

It is important to note that G1 did not see his relationship with G2 as a poor relationship, and never described his autistic younger brother in negative terms beyond expressing frustration at his destructive behaviour.

Positive sibling relationships were also described by children with older autistic siblings. But their relationships conformed to the hierarchical structures of Korean sibling relationships and, regardless of autism, the same norms were applied. For example, F1 (Case 6, younger sister) recorded fighting with her autistic older sister but their mother was with the children (Figure 6-3).



**Figure 6-3** Physical Fighting between Siblings (Case 6, home movie-6, time lap 02:07)



In this context, their mother reminded F1 that she should not hit her older sister and reminded F2 that she should discipline her younger sister. This was despite the fact that F2, who is autistic, might not understand and that F1 had claimed unfairness.

Maintenance of normative sibling relationships created ambivalence in younger siblings of autistic children (see also section 5.4.1.). For example, A1 (Case 1) described her relationship with her autistic older brother as '*sang-gwan-eom-neunde*' (I don't mind) '*gwen-chan-ah-yo*' (it's ok), but having an autistic brother or sister may have a negative impact on sibling relationships:

- A1:** He always is getting on my nerves. He turns strongly against us [the family].
- Interviewer:** What do you do?
- A1:** I just try not to get too stressed out

(Case 1, reviewing session)

Exceptionally, one younger sibling (Case 3) described the relationship with his older autistic brother as a friendship.

- Interviewer:** Do you think C2 seems like an older brother?
- C1:** No, I don't

**Interviewer:** Do you mean he seems like a younger brother?

**C1:** No, never. He seems like my close friend.

(Case 3, reviewing session)

C1 was clear about his status as a younger brother but showed that companionship plays a key part of his sibling relationship. The ambivalence apparent in other younger siblings' accounts may reflect the tension that arises as a result of role reversal and the adoption of obligations not normally associated with younger siblings. But despite awareness of disturbance to the normal rhythms of sibling relationships, the siblings engaged in ordinary communication and activities with their autistic brother or sister.

### 6.3.2. *But Different*

All the children in this study were conscious of the differences between their sibling relationships and those between normally developing children. For instance:

**Interviewer:** In your video diary, you said that your brother is not different.  
Why do you say that?

**H1:** But I did not mean he [H2] is not disabled.

(Case 8, reviewing session)

The nature of difference in the sibling relationship is closely linked to the characteristics of autism (Kaminsky & Dewey, 2001), and the siblings in this study were aware that this difference carries negative connotations, expressed through feelings of annoyance, anger, unfairness, hate, embarrassment, and sadness. For instance, Figure 6-4 and the accompanying commentary shows that J1 (Case 9) feels very irritated by his autistic brother's obsessive behaviour.

**Interviewer:** What does he do if he wants to snack at night?

**J1:** He asks consistently with tantrum.

**Interviewer:** Until he gets it?

**J1:** Yes, I feel really annoyed and bothered. (Case 9, reviewing session)

**Figure 6-4** J2's Tantrum and Buying a Snack (Case 9, home movie 3-1, time laps 08:44, 10:40)



The children in my study articulated the differences associated with the impairments of autism (communication, behaviour etc). For instance, H1 (Case 8) commented that her sibling relationship was clearly different in terms of what her autistic brother could not do:

Honestly, I sometimes wonder what it would be like if H2 was a normal child. And I do wonder why he turned out to be so different. But when I see my friends' brothers and sisters it fascinates me how they can talk properly and they are normal. For some strange reason, even though my brother is not normal, it seems that the normal kids are more different and strange to me. I don't even think that my brother is handicapped, but when my friends' brothers and sisters speak properly, I think they are strange.

Sometimes I wish if only, one day, he could be a normal child, not autistic, normal, just once a day to be normal and talk to me properly. I think it would be so nice. I still think that. If I think about it, it is horrible that H2 will always be disabled until he dies. He will never be able to speak to me properly. It is unfair I won't be able to hear him speak to me until I die. I guess it is just the situation we are in, but it doesn't seem right. Before H2 dies I want to hear him talk properly just once and it would be enough. Other kids' brothers and sisters are not disabled and they will be able to communicate all their lives. But H2 is autistic and even if I just wish for once, one day for him to talk to me, he will never be able to. This is really unfair. (Case 8, Video diary-6)

She emphasized that her autistic brother was not able to talk to her, which leads to an awareness of difference in the nature of their sibling relationship.

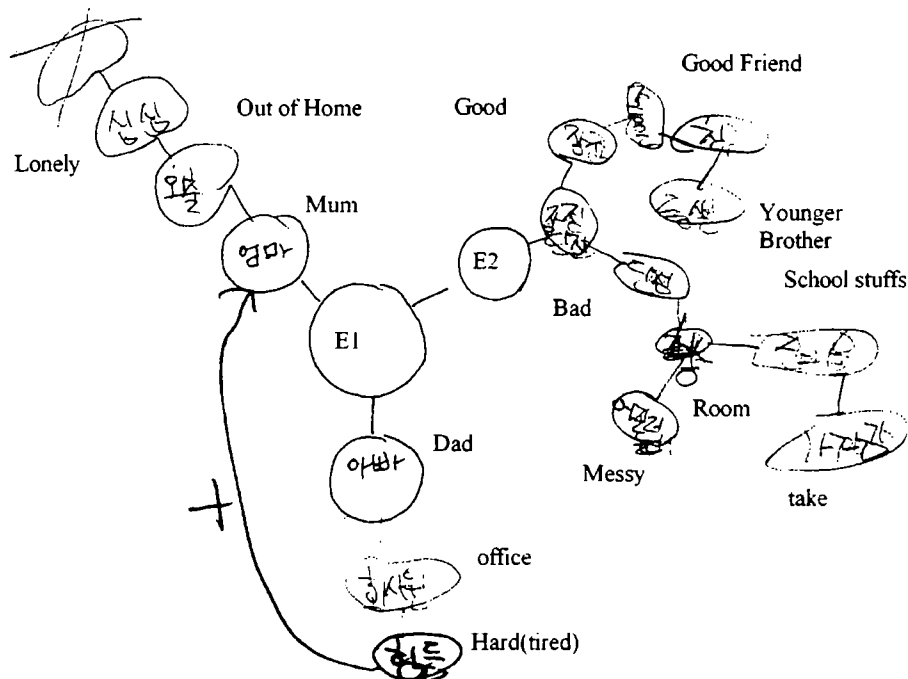
Four of nine siblings (Cases 1, 3, 5, and 7) in this study told me in reviewing sessions that they never talked to their school friends about their autistic siblings. They did not bring their friends home when their autistic sibling was at home, and the reason was that their friends might not understand what was happening in their daily life. Another reason was that there was no time left over for their friends because they must look after their autistic siblings.

In public settings, I found that the siblings' reactions were of three types that overlapped. I use three specific cases to illustrate these types: i) 'pretending I'm not his brother' (J1, Case 9), ii) 'looking at him from a distance' (H1, Case 8), or iii) 'hiding my autistic brother' (B1, Case 2). These reactions suggest that Korean siblings of autistic children feel oppressed or vulnerable to discrimination on the basis of difference. This sense of difference may increase when they enter school. The visible nature of autism means that siblings experience a continual vulnerability in their sibling relationships which may promote a sense of stigma, a theme to which I return in the following chapter.

As well as describing difference as 'part of life', the children also conveyed experiences of being largely invisible to people outside the family. For example, in Figure 6-5, E1 (Case 5) identified his younger autistic brother as: i) younger brother, ii) friend and iii) having disruptive behaviours. Although he depicted his brother as his friend, he realized that a big difference was the challenge of achieving a friendship with his autistic younger brother. He envied his friends who were able to play with their siblings.

Indeed, all the children in this study felt strongly about the challenges and differences in forming and maintaining particular aspects of sibling relationships in comparison with their friends with normally developing siblings.

**Figure 6-5** Spider-Web ‘People in My Family’ (Case5)



Unpredictable autistic behaviours are often frightening (Benderix & Sivberg, 2007). The children in the study found it difficult to understand or know how to react to these behaviours. H1 for example spoke of frightening behaviours in her brother such as obsessive, repetitive behaviours and impulsive emotional displays:

.... I find it very difficult to negotiate with him, for example, in a situation where I need to use the computer and my brother is using it. Even though I think he is enjoying it too much and he probably won't allow me to use it, I still ask him. I say, "Come on H2, can you move here so I can use it?" And he replies "I don't want to". ..... At first I would ask him to move, but if H2 is stubborn and if he doesn't move I give up. If I keep on telling him to move he starts having a tantrum. When he does it causes trouble. Once he starts his tantrum it is really difficult to calm him down. So mum tells me that I should try and understand him. I am scared that I might upset him so if he doesn't want to give up, I have to, and come back later for it.

(Case 8, reviewing session)

H1 sensed that she had to be prepared to withdraw. And she shows how the normative expectations of sibling relationships are reversed as she 'gives in' to H2's insistence rather than achieving his compliance.

These findings show how the children experience their 'difference' and have difficulties in achieving typical sibling relationships. In line with Kaminsky & Dewey's (2001) research<sup>45</sup>, my findings show that both the visible and invisible aspects of autism foster a sense of difference in siblings between: i) them and their autistic siblings, and ii) normally developing siblings.

## 6.4. Cultural Understandings of Sibling Relationships

In my study, relationships with autistic children resembled those of siblings in terms of *Jeong* and, *Woori*.

### 6.4.1. 'Jeong'

While there is no direct translation for *Jeong* in English, 'Jeong' in Korean culture is a heavily nuanced concept that conveys the experience of internal emotions and externally experienced connectedness with others (see Kim *et al.*, 2006:152-153). *Jeong* in this study is described, by the children, as one of the most common aspects of their sibling relationships. *Jeong* gradually grows over a period of time between autistic children and their siblings. The process of achieving *Jeong* was described by some participants as '*Jeong-deul-da*', which translates as '*Jeong* has permeated' or 'have *Jeong* with' (Yang, I.J. 2006: 286). The three youngest children aged seven and eight, (Cases 2, 4 and 6), did not describe sibling relationships as *Jeong*.

Regardless of gender similarity or difference, and birth order, *Jeong* evolves through engaging with siblings in day-to-day interactions over time. For instance, J1 (Case 9) defined *Jeong* as a combination of blood-tie and '*Woori*';

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<sup>45</sup> Kaminsky & Dewey (2001:406-407) have addressed the influences of particular features of autism on sibling relationships.

**Interviewer:** Do you think you have *Jeong* with J2? Do you think you have more *Miun-Jeong* (negative *Jeong*) or *Goun-Jeong* (positive *Jeong*) for your brother?

**J1:** Of course, I have [*Jeong* with my brother] because he is my brother. I have much more *Goun-Jeong*. Because we are brothers [indicating *Woori*]

(Case 9, reviewing session)

These words indicate that *Jeong* can develop within 'Woori' (see Choi & Choi, 2002). Another quotation shows that, *Goun-Jeong* can develop through strong 'affection' with an autistic brother or sister:

I like everything about my brother. That might be *Goun-Jeong*

(Case 5, reviewing session)

*Goun-Jeong* is an especially affectionate emotion for his autistic brother. Siblings tied by *Goun-Jeong* are more likely to give help and support to one another. Overall, the nature of *Goun-Jeong* is associated with blood-ties, having much *Jeong*, *woori*, and affection.

On the other hand, *Jeong* also encompasses the sense of hatred that siblings may feel for their autistic sibling's condition and resentment about its impact on their lives. However, these negative feelings about the condition of autism and its implications do not lead to the weakening of sibling relationships. An example is given by A1, who used the term '*Miun-Jeong*' in describing her concern about her autistic brother's illness;

'My brother caught flu today. Even though I was home he was in bed with pain and fever. Usually he is very healthy and never ill. I'm shocked and worried about him. I used to say that I hated him, but now I must have grown '*Miun-Jeong*'. When I came back home, he was in bed with pain and fever. I was really astonished and concerned because he never ever gets ill. I have always said 'I hate him', probably I have got '*Miun-Jeong*'. Anyway, I hope he gets well soon'.

(Case 1, video diary-7)

and A1 explains '*Miun-Jeong*' in the following fragment:

- Interviewer:** You said 'you may have *Miun-Jeong*'
- A1:** Yes
- Interviewer:** What is that? What do you mean '*Miun-Jeong*'?
- A1:** A hateful affection because he did hateful things
- Interviewer:** What?
- A1:** Being so close when he does really cute things he seems so adorable. So, when I see him I have bad feelings towards him but that's just how I feel at times. But he is still my brother... that sort of feeling.

(Case 1, reviewing session)

Although A1 has negative feelings of hatred and resentment towards her autistic brother, she still develops more *Jeong* (see e.g. Kim, S.H., 2003:111).

Siblings in this study did not describe only one type of *Jeong*. All had a mixed pattern of *Jeong* in describing their relationship with their autistic brother or sister. For instance H1 said:

If I look at considering things separately, I guess I have more *Miun-Jeong* towards him. But, now I'm used to it, and I sometimes realize it is difficult. But I see H2 behaving differently. I am just happy. It could be '*Goun-Jeong*'. (Case 8, reviewing session)

As H1 indicates, *Jeong* has developed unconsciously through direct and indirect interaction with her autistic younger brother over time and she has acquired both good and bad feelings towards him.

The findings of my study strongly indicate that *Jeong* as a Korean cultural concept plays a central role in shaping relationships between the children and their autistic siblings. *Jeong* is represented as having strong sibling relationships based on blood-ties, affection and even hate.



### 6.4.2. *Woori*

The siblings in this study expressed emotional and physical closeness to their autistic siblings and had a strong sense of *Woori*<sup>46</sup> (togetherness). J1 (Case 9) articulated this very clearly:

‘I am very happy that I have a brother like J2 and that he is a part of my family  
(home movie-5)

‘I am just very proud to have a brother like J2. He is cute, my cute little brother. I am very happy to have brother like J2.’  
(video diary-4)

‘At times, it is very difficult because of J2. but, if he’s not there I feel empty.  
(home movie 1-7).

**Interviewer:** Have you ever thought your life would be better without J2?

**J1:** Never, I am happier because he is with us.  
(reviewing session)

J1 describes how his autistic sibling is a part of ‘*Woori*’ in constructing his own interpersonal and interdependent relationships. He shows a strong emotional connection with his autistic younger sibling despite social interaction difficulties arising from his autism. Emotionally, J1 described J2, his autistic younger brother, in affectionate terms (*Jeong*) such as ‘cute’, ‘like’ and ‘happy’, even though he has significant psychosocial and behaviour problems. *Woori* captures the collective belonging where the collective is linked by *Jeong* (Choi & Choi, 2002;57), and *Woori* becomes stronger as *Jeong* grows deeper (Yang, I.J., 2006:286)

Six of the nine children in my sample also referred to physical aspects of *Woori* with their autistic siblings. For example, it was common for the children in this study to share

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<sup>46</sup> *Woori* translates as ‘group’ or ‘a collection of individuals’, the term used by collective members when referring to themselves in the collective context (Yang, I.J., 2006:286). The characteristics of *Woori* are emotional connectedness (*Jeong*, closeness, mutual-acceptance), oneness, sameness, and strong ties (e.g. Choi & Choi, 2002). *Woori* refers to a collective ‘we’-ness (Choi & Choi, 1990). Negatively, without ‘*Woori*’ people can be, and feel, excluded (see *Ijil* chapter 3: 3.2).

a bedroom with their autistic sibling (Figure 6-6) and in one case this crossed normative expectations relating to gender and sharing of rooms (see Figure 6-7).

**Figure 6-6** J1's Own Room (up) (Case 9, video diary-4, time lap 18:12) and Bedroom (below) (Case 9, home movie 14-1 time lap 02:33)



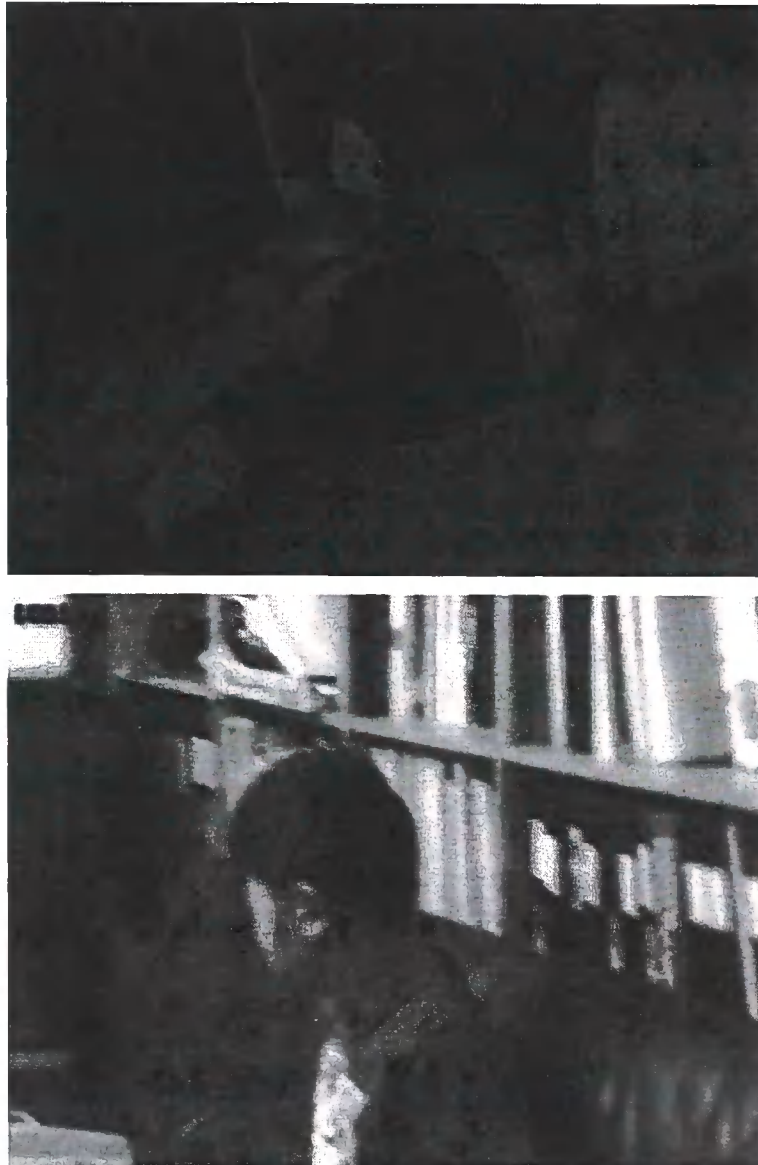
**Figure 6-7** H1 and H2's Room (Case 8, home movie-1, time lap 00:47)

This type of geographical togetherness across genders is not common in Korea. Here, the physical aspects of *Woori* bring negative implications as siblings may easily feel threatened or bothered by the unpredictable or aggressive behaviours of the autistic child with whom they share the room. The following example (Figure 6-8) and quotation from a home movie made at 5 a.m. show how J1 is disturbed by the erratic sleep pattern of J2.

- J1:** It's now 5 am. J2 woke up 3am to do his home work but he is still not in bed yet. He may go to bed soon.
- Mother:** It's time to go to bed. J2, will you go to bed now?
- J2:** Ah
- Mother:** No, You should go to bed so you can get up for school.
- J2:** Kiki [kiwi]
- Mother:** I will buy some kiwi for you.
- J1:** I think he won't be able to wake up in the morning.  
He is going to be late for school.

(Case 9, home movie 18)

**Figure 6-8** J2's Erratic Sleep Disturbance (Case 9, home movie 13-4 (up, time lap 00:28), home movie-18 (below, time lap 29:38))



Nevertheless, although J2's erratic sleeping pattern could upset J1, he showed a high level of tolerance and willingly agreed to share space with J2 even though he had his own room.

I think he sleeps earlier tonight. J2 usually sleeps around 12 or 1am, but when he is tired he goes to bed at 10 or 9 pm. When he sleeps around 9 or 10 pm, he usually wakes up early in the morning and wakes Mum up also. When he wakes up early he turns on the computer and listens to nursery rhymes. When Mum, Dad and I tell him to sleep he doesn't always listen, but when we turn the light

off, and put on a gospel tape for him he falls asleep in 10 minutes. I share a room with J2. I like having J2 next to me.

(Case 9, video diary-8)

In this way J1 emphasized togetherness and interdependency which are characteristics of *Woori* (Choi & Choi, 2002:62).

C1 (Case 3) shared a room with his older autistic brother but their older sister had her own room. He talks about sharing a room and sleeping next to his autistic brother in terms of companionship ('*Woori*')

**Interviewer:** Do you like sleeping with your brother?

**C1:** Yes

**Interviewer:** Why?

**C1:** When I'm alone it is scary and boring sometimes.

**Interviewer:** Why are you bored when you sleep? Do you have to do something before bed?

**C1:** No, but before we sleep we play badminton lying down sometimes.

**Interviewer:** Just the two of you?

**C1:** We play lying down. I pick it up when it falls and I also watch my brother playing and then I fall asleep.

(Case 3, reviewing session)

C1's account provides a good example of how shared space for sleeping and joint activities give opportunities to develop *Woori* with his autistic brother. All the home movies taken by all children show events that portray *Woori* as a significant aspect of relationships between the children and their autistic siblings who are a crucial part of their identity.

Taking all the data produced by the children in this study, it becomes apparent that '*Woori*', associated with togetherness and emotional 'one'ness, creates strong relationships and interactions between autistic children and their siblings. Despite the

difficulties of engaging in reciprocal interactions, sibling relationships take on a deeper meaning than merely tolerating or simply getting along over time.

### **6.5. Parents' Views of Sibling Relationships**

Interviews with parents portrayed the relationships between their normally developing and autistic children in very ordinary terms, as positive or, at least, 'not different'. They were aware that their normally developing children had been affected by the presence of the autistic sibling, but did not perceive any negative impact on the relationship between the siblings. For example, one mother argued that her children's relationship was like the relationship between any siblings.

Some mothers say if a disabled child has a sibling, it could be hurtful for them. I tell them: 'don't say such things, life is the same'. They manage to survive in every given situation. It is better to have an autistic sibling than none. Even though the world is not easy on them, they are just children now. When they grow old, they will have their family who will look after them, although the generation will change and I think they will take care of their autistic brother or sister. They know it is fate and blood-relationships, family always come before others. This is what I think.

(Case 2, B1's mother)

This mother's account suggests that sibling relationships where one sibling is autistic follow the same normative expectations as the relationships between normally developing siblings. Parents emphasized the strength of the blood-tie and how this was of far greater importance than any negative effects, feelings or perceptions associated with the sibling relationship. For example, when I asked A1's father (Case 1) how A1 and A2 got on, he explained:

To put it simply, their mum gave birth. They share the same womb, and blood.

All parents suggested that particular patterns of gender and birth order supported more effective development of *Jeong* and *Woori* between siblings. The ideal pattern was seen as same gender siblings with an older normally developing child. For example, when I asked the mother of H2 (younger autistic brother) and H1 (older, sister): What if H2 was a girl? She responded:

**Mother:** Probably it would be 'good'. Perhaps I would have looked after her better. They could have a bath together, share a room. These would not be problems at all if he was a girl. I think they would have more shared time together.

**Interviewer:** And if their birth order was different? ... For example if H1 were younger and H2 older?

**Mother:** As a parent, it wouldn't have been good. It is better for the younger child to be autistic. If the elder was autistic I think the younger child would have a very difficult time.

(Case 8, H1's mother)

Other factors that, according to the parents, contributed to successful sibling relationships were: spending plenty of time together, sharing private space, and the development of coping strategies<sup>47</sup> by the non disabled sibling in responding to the challenges presented by the behaviour of the autistic child. These factors are also characteristics of *Jeong* and *Woori*.

Consistent with the children's own accounts, parents indicated that the relationships between the autistic children and their siblings changed in line with their developmental stages. One mother (Case 9) described a big change in her adolescent son with younger autistic brother. From being a child who had negative feelings and avoided involvement with J2, his autistic brother, he began to share caring responsibilities and develop a

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<sup>47</sup> These included both active and passive strategies (e.g. De Boo & Wicherts, 2009): seeking parental support in responding to 'obsessive behaviours', talking with parents if experiencing negative feelings such as sadness, anger or frustration about, or towards, their autistic siblings, developing understanding of autistic children's behaviours over time, spending time with friends, developing communication skills with autistic children, doing physical exercise, engaging in religious activities, responding immediately to siblings' demands, avoiding talking about autistic siblings outside the family, avoiding physical contact with the autistic child.

closer relationship with J2, despite his destructive behaviours. In the interview with the mother she told me:

He [J2] scribbled on brother's notebook and textbook. He likes his brother's belongings. Although I do not allow him to go in J1's room, he often makes lot of problems in his brother's room. But J1 now does not mind his brother's behaviours and says 'it's OK'. One evening J1 said '.....I have also changed gradually with J2'. I know he [J1] also faces the challenges raised by his brother's behaviours. Now, he looks on the positive side and is getting on well with his brother.

(Case 9, J1's Mother)

An exception<sup>48</sup> was Case 8 in which the parents of H1 described how the relationship between their adolescent daughter and her younger autistic brother did not follow normative expectations, despite their blood-tie. The father described the change: '*now, their relationship has changed like 'you are you, I am me.'*' The parents were concerned that individualistic familism<sup>49</sup> would hinder the development of sibling interdependence. All parents in this study expected, without question, that their normally developing children should accept and gradually share caring responsibilities for their autistic siblings. They also expected that strong and positive sibling relationships associated with *Jeong* and *Woori* would develop and endure over a life time.

## 6.6. Summary

In this chapter I have explored children's experiences and perspectives of their autistic siblings, and the changing nature of their relationships over time. The children's views

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<sup>48</sup> But H1's accounts of her relationships with autistic younger brother were different to those of her parents.

<sup>49</sup> Under individualistic familism, the nature of the relationship between family members is based on egalitarianism, reciprocity, human dignity, and virtue (Choi, S.J., 2004:s73). Chang, K.S. (2003:600) mentioned that 'individualistic familism in South Korea is hinged upon two social trends, namely, social democratization nurturing the development of individuality in regards to women and youth [children] and commercialization of domestic life amid the rapid expansion of consumer capitalism. While individualist familism was initiated in the West, it has spread rapidly into South Korean society under the compressed processes of economic growth, democratization, Westernization, and even economic and cultural globalization'.



about their autistic siblings were not static, but had changed over time as the children learned to cope with the everyday realities, and changing features of their siblings' autism. All but the three youngest children (seven and eight years) in the sample demonstrated a process of reframing their experiences to develop more accepting and positive attitudes towards their autistic siblings. Studies employing social psychological perspectives (see chapter 2) have tended to focus on 'problematic aspects' or 'deficits' in relationships between children and their autistic siblings and indicate less positive affect in the siblings of autistic children (Bägenholm & Gillberg 1991; Knott *et al.* 1995; Kaminsky & Dewey 2001; Orsmond & Seltzer, 2007a). Acknowledging the contrast in research methods, the children in my study revealed awareness of positive aspects of their relationships with their autistic siblings, citing joint activities, effective communication, and the strong cultural value of sibling relationships. But they also acknowledged 'difference' in developing and maintaining relationships with autistic siblings. Overall, children's views fluctuated in regard to relationships with their autistic siblings, but they perceived their siblings as brother or sister rather than as 'autistic'.

The distinctive findings in this study were that the six older children also referred to *Jeong* (strong interpersonal ties) and *Woori*, ('we'ness). The children and parents' accounts of sibling relationships in this study are informed by Korean cultural norms. In particular, 'mixed *Jeong*'-based sibling relationships (found in the six oldest children) were perceived as deep and lasting, although one father (Case 8) has concerns about an influence of individualistic familism on sibling relationships. Strong relationships were also associated with *Woori*, in which togetherness and emotional closeness promote strong interpersonal relationships. In the next chapter, I go on to explore siblings' everyday lives in family and wider society contexts.

## **Chapter Seven**

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# **Constructing ‘Ordinariness’ in Siblings’ Everyday Lives**

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## 7.1. Introduction

As outlined in chapter 2, research on the effects of living with a disabled child has focused predominantly on the complexity and hardships of life (e.g. Moore *et al*, 2002; Miller, 2001). My study focuses on siblings' constructions of the realities of their everyday lives within the home and wider society. Having explored the meaning of being a sibling of an autistic child (chapter 5) and the experience of these sibling relationships in the Korean context (chapter 6), in this chapter I: i) explore the reality of living with an autistic sibling as an integral and ordinary part of everyday life, in a way that focuses on the positive as well as the negative and ii) examine the ways in which siblings reframe autism within a cultural context of negative attitudes towards autism.

## 7.2. Seeking and Achieving Balance in Everyday Family Life

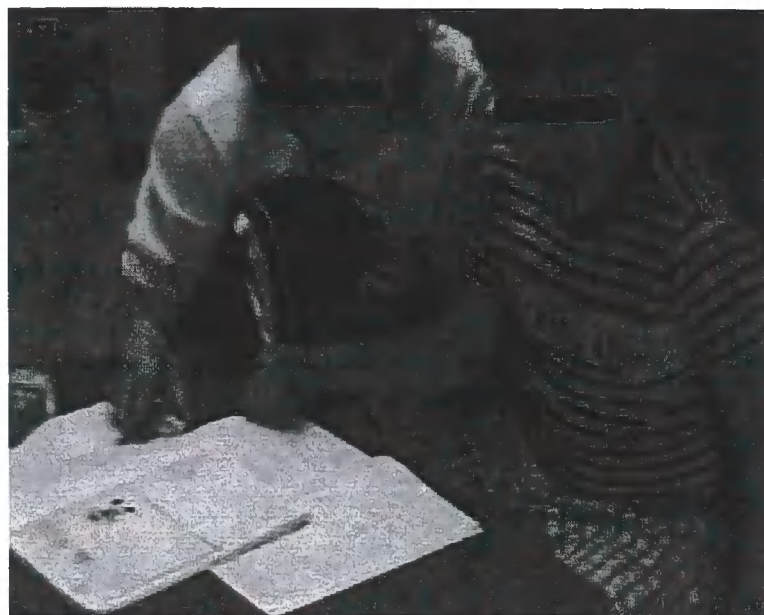
Family contextual factors play an important role in shaping sibling relationships in families where at least one child is disabled or chronically ill (Taskinen, 2003). In the Korean cultural context, characterized by Confucian familism, the family context implies strict adherence to the principles of filial obligation (Lee & Sung, 1998). In families with an autistic child, filial obligation has particular implications for the expectations that parents have of their normally developing children and the experiences of normally developing children in their daily lives. The following section describes how the children in the sample negotiate balance between the negative and positive effects on their everyday lives as siblings of autistic children.

### 7.2.1. *Accepting Different Parental Treatment*

All children's and parents' accounts in my study made it clear that parental attention is heavily focused on the autistic child. A lack of services, and of support through social networks, accentuated this concentration of parental attention, leaving less time to spend with, or focus on the emotional wellbeing of, the siblings of autistic children. J1 (Case 9) showed a lack of parental support or significant time sharing through his home movie (Figure 7-1 and Figure 7-2):

J2 has returned home from the swimming pool with mum and he is doing homework now [with mum]. (J1's commentary from home movie-10 in reviewing session)

**Figure 7-1** Mother and J2 Doing Homework (Case 9, home movie 1-9, time lap 04:35)



Mum is always very busy cooking and looking after J2.

(J1 commentary from home movie 17-1 in reviewing session)

**Figure 7-2** Mother Cooking and Looking after J2

(Case 9, home movie 17-1, time lap 26:31)



Lack of parental time and attention often led to feeling of loneliness and regret (see figure 6-5). For example, E1 (Case 5) talked about 'being left alone':

Then, today, E2 and mum were out of home. ...[Mum] was always out of home [with my autistic brother] ... I like it when mum is at home. (video diary-1)

G1 (Case 7) expressed similar feelings in a reviewing session:

**Interviewer:** After school, do you stay alone at home?  
**G1:** Very often .....I don't like it if Mum is not in when I return home.

All children in the sample expressed the feeling that they had little opportunity to share their thoughts and feelings with their parents. In response to being asked about sharing his thoughts with his mother and father in a reviewing session J1 (Case 9) responded:

**J1:** Never  
**Interviewer:** How about friends?  
**J1:** No, not really, it's secret. I never talk about me to others.  
**Interviewer:** Never? Who do you talk to about your thoughts?  
**J1:** It depends on the situation, I decide whether it would be better to talk to parents, or to friends, or teachers.  
**Interviewer:** Do you? Have you communicated frankly with your parents?  
**J1:** If I want to buy something, such as a Gameboy. But, they generally do not listen carefully.

(Case 9, reviewing session)

Siblings' accounts suggest doubts about the degree to which their parents take them into consideration, and unsure feelings about the value of their family life. This was well illustrated by G1 (Case 7):

G2 is playing now. G2 is playing with cards. My dad is sleeping now and mum is watching TV. I am wondering - my family is happy now?

(Case 7, video diary-7)

Nevertheless the children's accounts also conveyed their acceptance of the lack of parental attention and support in everyday life. They were explicit in describing the different needs of their autistic sibling and their parent's limited availability. As H1 (Case 8) said:

Mum and dad would like to give us equal attention, but they pay more attention to H2 because of his disability. Literally, mum and dad should give attention equally. But H2 has been paid more attention. They are concerned about H2's limitations, so they should pay more attention, and more time with him. As a result, they cannot pay attention to me, although they would like to

(Case 8, reviewing session)

H1's comments suggest that she is willing to understand and accept this consequence of having an autistic sibling. Eight of the nine children in the sample presented similar understanding and acceptance. F1, the one child who did not show such understanding was one of the youngest. The children reframed past and current experiences to explain why they receive less parental time and attention in the family context. In particular, they expressed a desire not to further burden parents with problems by highlighting the lack of their parents' availability. And the data show that they are constantly mindful of their parents' limited ability and their autistic siblings' vulnerability.

By accepting the lack of parental time and attention, the children reframe their experiences to incorporate an understanding of their parents' situation and show compassion in not making additional demands. I suggest that these responses indicate strengths among the siblings of autistic children that help to maintain the integrity of the family as a unit. This contrasts with arguments about the vulnerability of the family unit which is highlighted in much of the literature on the consequences for families with autistic children, arguments that may offer biased accounts and misunderstandings of siblings' lived experiences.

### *7.2.2. Accepting Second Place*

An important theme that emerges from the study is that the children understand and accept that their autistic sibling's needs are placed before their own, and overshadow

their lives. They do, however, express a desire for additional resources and attention, feel that their own needs are not being met, or are not seen as important in comparison with the needs of their autistic sibling. G1 (Case 7), older brother to G2, offers an example:

- Interviewer:** What is your position in your family?  
**G1:** Might be lower than G2's.  
**Interviewer:** You mean, although you are older brother?  
**G1:** Mum and Dad give many things to G2 [rather than me]  
**Interviewer:** Why?  
**G1:** They give G2 what he wants immediately, because he pesters them constantly. Therefore, they do whatever he wants as soon as possible.  
**Interviewer:** How about if you ask something?  
**G1:** They always do it later. If I ask them to do something for me, [parents] say 'you are the older brother, so you should wait'. And when I would like to go on the computer, while G2 is playing on the computer, but G2 has already been using the computer for a long time, I tell Mum 'I also would like to go on the computer', Mum scolds me

(Case 7, reviewing session)

G1's comments indicate treatment according to a different set of rules from their autistic brother or sister, rules that involve siblings being asked to withdraw, or minimize their personal needs.

H1, older sister to H2, had experience of being denied new clothes, shoes and a mobile phone [not a luxury] because of her brother's more pressing needs. Although she accepted this, she explained that she would try and avoid imposing a similar situation on any children she may have in the future:

I would like to have a baby if I get married. In the past, I wished I would have two babies. Anyway, if the first baby is born with autism, we will look after him only ..... to avoid any disruption to the lives of other children. I think that's better. I have already had experience because of my brother, so [if I have a child with

autism] I think I can do better than any others. It is also a big difficulty if the older one is not born with autism and the second one has autism. The older one can be affected again. For this reason, I would like to have only one baby

(Case 8, reviewing session)

H1's comment is that autistic children receive priority more often and easily than their siblings.

Although the children recognized the more urgent needs of their autistic siblings, in the case of F1 (Case 6), aged 8, the perception of having to take second place accentuated her sense that her autistic sister was considered to be more important than her in the family system. She presented with hyperactive behaviour whenever she could not get her mother's attention. Although her mother acknowledged that F1 needed more time and attention, she also commented that F1 felt that her parents' energy, availability and attention continued to be inappropriately allocated to her autistic sister, threatening her place and position in the family system. In this case, the unequal attention paid to F1 and her sister had had a significant impact on F1 who was receiving psychiatric attention as a result of her hyperactive behaviour<sup>50</sup>.

The other eight children in the study employed effective strategies of minimizing their own needs in order to maintain equilibrium in the family. For example, C1 (aged 13, Case 3):

**Interviewer:** Do you think Mum and Dad give you less attention than your brother?

**C1:** Yes

**Interviewer:** Did you think it is unfair?

**C1:** Sometimes regrettable, but that's it.

**Interviewer:** What do you mean 'that's it'?

**C1:** I think it is unavoidable.

(Case 3, reviewing session)

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<sup>50</sup> There was no suggestion of a diagnosis of autism for F1



And A1 (aged 15, Case 1):

- Interviewer:** If your parents have a parents' meeting at school, but they also have to go to your brother's school, what do they do?
- A1:** Never, Mum can never attend [my] parents' meeting. She goes to my brother's school. So, she can never attend [my school].
- Interviewer:** Is it OK for you?
- A1:** Yes it's alright. I just said 'Mum, you cannot come today',
- Interviewer:** How do you feel about that?
- A1:** Sometimes a bit of regret, but I understand why she cannot attend. (Case 1, reviewing session)

These comments show how children accept that some differences in the way they and their autistic siblings are treated may be unavoidable. Although they recognize that the autistic sibling gets a disproportionate amount of time and attention, they do not complain about the inequality or unfairness. The children's relegation of their own needs represents an adaptation to the additional needs of their autistic brother or sister.

The question of parental attention, however, is complex and is not always consistent. For example, J1 (Case 9) perceived that his parents sometimes gave him equal, or even more attention than his autistic sibling:

- Interviewer:** Do you think mum and dad give you as much attention and love as J2?
- J1:** Yes, I think they give me more
- Interviewer:** More?
- J1:** (Yes)
- .....
- Interviewer:** Didn't you say J2 gets anything whenever he demands<sup>51</sup>?
- J1:** Yes, because J2 does not speak
- Interviewer:** Well, don't you think it's unfair?
- J1:** Never
- Interviewer:** Never?

<sup>51</sup> J2 has a habit of throwing tantrums when he does not get what he wants immediately

**J1:** When I was in year 1 and 2 [at school], they [parents] bought much more for me than J2

.....

**Interviewer:** ..... and you mentioned that even when your mum was really busy, she taught you when you prepared for examinations.

**J1:** Yes, even though she was really busy. When I was preparing for examinations, J2 was allocated 20 or 30 % of their time. [My parents] coached me to get high marks.

(Case 9, reviewing session)

Although siblings of autistic children may generally be given a lower level of priority, some perceived that they have been given priority in such things as the balance of material possessions, and parental attention and time for specific issues. Moreover, siblings in this study acknowledged that their parents attempted to treat them equally, although they were not always successful in doing so.

Although the sense of taking second place could be aggravated if already feeling neglected, the children generally minimized the consequences and accepted this as unavoidable. In other words they accepted second place and made a virtue of their role in maintaining family equilibrium.

### ***7.2.3. Losing & Gaining in Daily Family Life***

The data revealed further themes of children's adaptability that focused on disruptions to wider family life in order to respond to the needs of their autistic siblings and had a direct impact on the lives, plans and routines of the children in the sample. Talking about earlier times when the family lived in Thailand, H1 (Case 8) said:

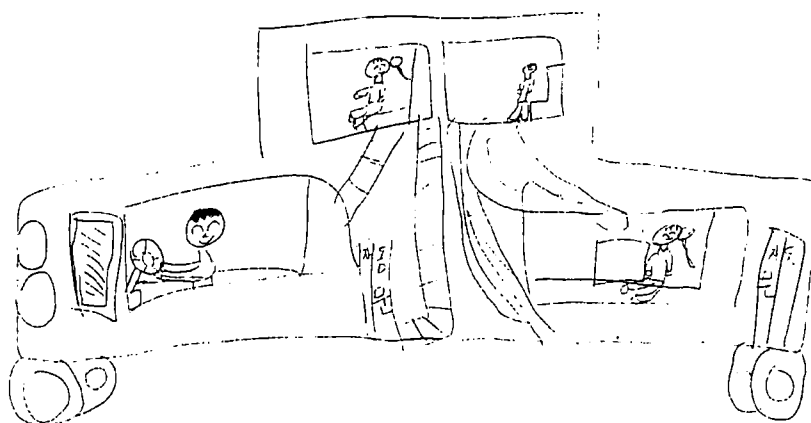
I wished I had stayed in Thailand. Due to my brother's autism, we came back to Korea after we knew his diagnosis. We could not do anything [because of H2], so we moved to Korea where there was a special school for autistic children. Honestly, if H2 did not have autism, we might have stayed longer in Thailand. I really did not want to come back to Korea. When we first came back to Korea, we had to move house frequently. When I entered nursery, I was not really

familiar with everything. So I was often scolded by the teachers. When I entered elementary school, I could not make friends. I did not adjust to school because I came from Thailand. I think it was all because of H2. I wish I could go back to Thailand now but I can't because of H2.

(Case 8, video diary-11)

All siblings in my study depicted episodes of how their lives are disrupted by their autistic siblings. They spoke of restriction in family activities, which are often changed or given up. For example, in Figure 7-3, D1 (aged 8, Case 4, older sister) shows the restrictions placed on family activities because of her six year old autistic brother's distress at changes in the environment.

**Figure 7-3** D1 draws her family going to an amusement park (Case 4)



In discussing her drawing with her D1 explained that the family sits separately, the father is the driver, the mother sits in the rear seat. D1 sits on the top, in front with her brother D2 behind her. The children can go to their parents using the slide (D2) and ladder (D1). The family is going to an amusement park by car, something D1 has long wanted to do. But every time the family has attempted such an outing, D2 has become distressed and refuses to get out of the car. [D1's mother also explained that the family never gets beyond the car park, instead driving round the car park, and coming back home immediately.] The result is that D1 never gets to realize her dream and she is clear that this is the result of her autistic younger brother's behaviour.

Another feature of the disruption of daily routines and activities is the lack of respect for the children's privacy shown by their siblings. Their home movies show that boundaries are continually crossed and privacy invaded by their autistic siblings, who have poor social skills and lack insight into the impact of their anti-social behaviour.

None of the children in this study were able to spend time alone in their rooms without being disturbed by their autistic siblings, a clear source of tension and irritation. For example, the continual threat of disturbance meant that school aged children were often unable to study at home:

**A1:**                   ....., I can only study at the *hakwon* head teacher's home.

**Interviewer:**   Why?

**A1:**                   I could not study at home because of my brother

(Case 1, reviewing session)

Sharing the physical living environment was problematic, particularly where siblings were of different genders (see section 5.3.1.)

Despite frustrated ambitions and invaded boundaries, seven of the nine children's narratives (Case 1, 2, 4, 5, 6, 7 and 9) do not focus on the restrictions of everyday life. Rather they focus on the ordinary activities of daily life and the routines in which they engage with their autistic sibling. This focus reflects Korean family values that demand the continual integration of their autistic children in family life as part of '*Woori*' (see chapter 6). In other words, the children's perceptions of their autistic siblings and the value of family cohesion result in their ready accommodation to the needs of their siblings in order to ensure inclusive family life. Five of the nine children (Case 3, 4, 6, 8 and 9) in this study depicted family outings, trips to the shops and park, and dining at restaurants in their home movies (see Figure 7-4).

Despite the disruptions brought to J1's family life by his younger autistic brother, Figure 7-4, a family dinner in a restaurant, shows that continuity of family life is maintained in ordinary cultural ways. The inclusion of autistic siblings in daily activities helps children to reframe their more difficult experiences and maintain a perception of 'ordinary family life'. In spite of disrupted physical boundaries, six of the nine children (Case 3, 4, 5, 6, 7, and 9) preferred to share their room with their autistic sibling. And

none of the children suggested that their schoolwork was affected despite disturbances while they do their homework.

**Figure 7-4** Dinner with Extended Family at Korean Traditional Restaurant.

(Case 9, home movie 12-2, time lap 46:35)



To summarize, although the children perceived their daily lives being controlled, to some degree, by their autistic siblings, they made sufficient accommodation to ensure that their autistic siblings were integrated into the routines of family life.

#### ***7.2.4. Broader Perceptions of Family Life***

Although the children in my study experienced challenges in living with and responding to the needs of their autistic siblings, this is not the whole picture. In recognizing the additional pressures on family life, and being consciously aware of the cultural obligations of filial duty, all the children gained enhanced understandings of family life, showing empathy and compassion towards their parents and autistic sibling and willingness to share in the work of caring for their autistic sibling. For example, J1's mother is the primary carer for J1 and his autistic younger brother. The father is rarely involved in 'hands on' caring for his children. J1 shared the caring tasks in order to minimize his mother's burden:

- Interviewer:** If someone was to help your family, what would be the most important support?
- J1:** My family would not need any help.
- Interviewer:** Why?
- J1:** My family looks after J2, he has been taught everything by Mum. Yes, it was very hard but I and my family accept that it is our life now. I also help Mum to take care of my brother.
- Interviewer:** Do you? Why ?
- J1:** To give Mum a break. (Case 9, reviewing session)

Here, J1 suggests that his mother would be overwhelmed without some break from the ongoing demands of caring for his autistic brother. This led to his strong willingness to have a caring role for his autistic sibling.

The six oldest children clearly expressed their felt obligation to help care for their autistic siblings (see chapter 5) and all children accepted their involvement in caring as part of the normal routine of daily life. For the six oldest children this included short periods of sole responsibility. For example:

If my mum is not at home, and dad comes late, I always look after G2

(G1, aged 12, Case 7, reviewing session)

The caring tasks undertaken by children followed a gendered pattern, typical of Korean cultural norms (e.g. Won & Pascall, 2004). The four boys in my study attempted to help supervise, protect or guide their autistic brothers while the five girls engaged in more practical tasks usually seen as 'maternal', such as feeding, dressing, toileting, and playing.

The acceptance of care responsibilities for siblings did not go unquestioned. Three of the nine children (Case 1, 3, and 6 girls aged 15 and 8 and a boy aged 13) expressed some reluctance based on the consequences of caring including isolation from peers,

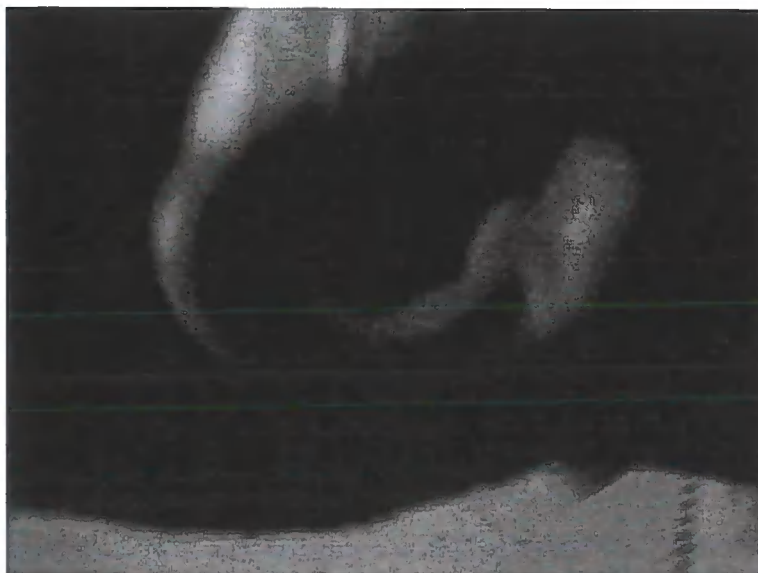
restrictions on their social life, and expressed a degree of resentment at the high level of parental expectations on them.

The children showed a high degree of independence and, arguably, received less parental support than might be expected in contemporary Korean society. G1 (aged 12, Case 7) and J1 (aged 13, Case 9), for example, talked about their experiences of injury in their video diaries. (see Figure 7-5, and 7-6).

**Figure 7-5** Injured Toe (Case 9, video diary-13, time lap 21:23)



**Figure 7-6** Injured Ear (Case 7, video dairy-10, time lap 00:49)



In Figure 7-5, J1 shows an injury sustained when playing basketball, and in Figure 7-6, G1 shows his ear following a visit to the GP for minor surgery and the pharmacy to buy tablets. Discussing these images in the reviewing sessions it became apparent that J1 and G1 had not expected their parents to accompany them when seeking treatment. G1 was obliged to telephone his mother from the pharmacy when the pharmacist insisted on speaking to his parent. In an interview with G1's mother she explained that she often uses the phone to support G1 since she is limited in her ability to accompany him physically because of her caring responsibilities for his autistic brother.

The six oldest children in the sample were quite accepting of the lack of support for them personally. For example, in responding to a question about help in the reviewing session H1 said:

To be honest, I don't mind not getting any help. But I think I can manage by myself ..... It would be better if my family could help him even more. In other words, I don't need help. (Case 8, reviewing session)

As these three instances indicate, being the sibling of an autistic child can be associated with rapid learning of independence, self-reliance, and self-confidence, skills that are integrated into their ordinary, daily family life. These findings also suggest that, for children with autistic siblings, the family may be a source of obligation rather than a source of support. In order to make sense of these positive and negative experiences, the children appeared to develop an understanding of family life through reframing their experiences as part of ordinary family life. In the following section I move on to address the children's experiences beyond the family, in wider social contexts.

### **7.3. Reframing Ordinary Daily Life in the Wider Society**

In chapter 2, I argued that previous research on the lives of siblings of disabled children has tended to focus narrowly on the psychological adjustment or maladjustment of siblings, rather than on their place within wider sociocultural contexts. But children's daily lives need to be recognized in a wider context, because their experiences are



influenced by the sociocultural norms and values surrounding autism, which establish the boundaries of children's daily life in wider society.

### **7.3.1. *Living with Autism***

Explicitly or implicitly, the everyday lives of the children in this study are subjected to the consequences of living with an autistic sibling. All the children in this study have experienced shame and social exclusion, the result of prejudice against and wider, stereotypical views of autism. These disabling attitudes also contribute to the experience of 'stigma by association' (Burke and Parker, 2007) in social situations. For example, H1 (Case 8) talking about her younger brother described an episode:

..... He sometimes goes out of the house by himself. And he once suddenly disappeared without saying anything. Mum often looks for him. Last time, we assumed he was in the park. I saw my brother with middle school students and their boy friends, especially the girls wearing my school uniform and in the upper year in my school. They imitated my brother's speaking. The boys imitated my brother's behaviours. I was really embarrassed but I had to bring him to home safely. So I sat on a bench and phoned Mum 'I am in the park, but I cannot take him out [from the group]'. Later, I could not bear it anymore, so I brought him home. I really disliked it when we went to the park. My brother had misbehaved in front of a couple who were dating. The man imitated my brother's behaviours. I thought they were really bad, but my mum did not think their behaviours were bad. Instead she just thought they were having fun with my brother.

(Case 8, reviewing session)

Here, she expressed her anger against public stigmatizing public reactions towards her autistic sibling's challenging or atypical behaviours. The children were often confronted by stereotyping attitudes towards their autistic sibling as well as themselves. As a result, families of autistic children were often isolated. A1 (Case 1) described another episode in a reviewing session:

**A1:** Last time, my mum and brother were walking across the pathway on the mountain. A lady said, 'I won't come here, because of him'. Because of my brother. Then, my mum was shocked, speechless, she came home and talked to us.

- Interviewer:** What did you do?
- A1:** I was terribly annoyed with that lady, I shouted with anger  
'Who are **you**?' [to talk in that way].
- Interviewer:** What did you feel?
- A1:** Really hurt, yes (Case 1, reviewing session)

**Figure 7-7** Walking with Parents (Case 1, home movie-4, time lap 01:09)



As explained by A1, in many situations of everyday life, the children experienced the public rejection of their autistic siblings. Stereotyping public attitudes, which result from a lack of awareness, were a constant source of embarrassment, anger or worry. As Shin, J.Y. (2002) has argued, Korean families of autistic children do not find it easy to be open about their autistic child to people outside the family. In this context, through association, the children's lives were also subjected to a 'form of secondary experience'<sup>52</sup> (Burke, 2007:12) associated with autism. The following exchange reflects this sentiment:

- Interviewer:** If you go out with E2, are you OK with him?
- E1:** We hardly go out
- Interviewer:** Hardly? Why?
- E1:** Mum never allows us to go out with him.

<sup>52</sup> Burke (2004) suggested that siblings perceived themselves as disabled by the fact of having disabled brother or sister.

- Interviewer:** Never?
- E1:** Almost never
- Interviewer:** Why?
- E1:** Because it could be dangerous.

(Case 5, reviewing session)

Due to the characteristics of autism, social acceptance and inclusion are harder to achieve as they require awareness and understanding from the community. E1's words, above, suggest that his mother was concerned to protect him from negative cultural attitudes. As I showed in chapter 3, Koreans are influenced by deep-rooted beliefs about disability, manifested through fatalism or shamanistic thinking (Kwon, M.O., 2000) and as a source of shame to the family and their ancestors (Kim & Kang, 2003:145). In a Korean cultural context, if the symptoms of autism are visible, autistic people may be identified as mentally ill or learning disabled. For example, a common insulting term in current Korean youth culture, is referred to by H1's comment '*Aeja*' (slang for disabled people) or '*Michin*' (meaning mad or crazy). The latter is an adjective used to describe a person with a psychiatric problem and tends also to be an insulting remark used to refer to autistic children:

- Interviewer:** You said, sometimes, your friends talked about [your brother's disability] using offensive expressions, disability as a bad slang word.
- H1:** *aeja*
- Interviewer:** What does it mean?
- H1:** Disabled people
- Interviewer:** Do your friends often use the word?
- H1:** I have also used it. (laugh)
- Interviewer:** You as well?
- H1:** Yes, it is not an expression used about autism only. Rather, *aeja* means more generally 'like disabled people' 'people with mental problem'. Like about people with mental problems, we use '*aeja*'
- Interviewer:** Is it a bad word?
- H1:** Well, *aeja* is used about people with michin [crazy].

Indeed, we could hear *michin aeja* [crazy disabled people] to talk about people with mental problems. Those people whose moods change erratically.

(Case 8, reviewing session)

H1 described a situation where due to a lack of knowledge of autism in the community, the children struggle with traditional socio-cultural values of disability that effectively label disabled people as 'unusual' 'abnormal' 'handicapped' or 'disabled'. Importantly, H1's comments indicate that Korean children are still subjected to stereotypical attitudes to disability, rather than awareness acquired through the reality of having a disabled family member.

Two adolescent girls (Case 1 and 8) experienced judgemental reactions from friends linked to having autistic siblings. For example, A1 (Case 1) became annoyed when her best friend was judgemental about the implications of her having an autistic older brother:

When I was studying very hard, my best friend came and told me, 'I did not understand why you studied very hard. Well, now I understand. It's because of your brother'. I was really annoyed.

(Case 1, reviewing session)

This was particularly difficult for the children, as they were subjected to the stereotypes associated with autism. The children were not open about their siblings' autism, fearing that they may be subjected to pity, illustrated by the following two examples:

**Interviewer:** Doesn't [your friend] know your brother is disabled?

**A1:** I do not want to talk about him. [If they] know, they pity me.  
'Sympathy'

.....

**Interviewer:** Would you like to be with friends more?

**A1:** Yes, sometimes, well, except when they ask me 'who is your brother?' .....

One of my school friends asked me again, so I said 'you don't have to know about me'

(Case 1, reviewing session)

**H1:** I would more comfortable if I could talk openly to friends, but my friends do not understand. They don't know what I am talking about ..... No, I have no friends to share my deep thoughts and feelings. No, I have one.

**Interviewer:** Who?

**H1:** Me and myself.

**Interviewer:** You are your friend?

**H1:** That's right. Me and myself, myself is supposed to be the same age. That's right, my friend, friend in my mind.

(Case 8, reviewing session)

These accounts suggest elements of shame and loneliness associated with an inability to escape the culturally constructed belief system about disability (Kwon, M.O. 2000). Furthermore, they suggest that the children have difficulty in forming friendships with peers and both they and their autistic siblings have difficulty in accessing the wider community.

Nevertheless, the children's lives were not entirely bounded by autism, and all the children in the sample argued that having an autistic brother or sister is not the catastrophic experience that predominant cultural interpretations imply, for example, that the family is cursed or that the presence of a disabled child means a 'disabled family'. In H1's words:

Frankly, my brother has autism. That is true. But my family may live better than other families. People think my family might have a hard life and be unfortunate. I cannot totally disagree with them. Yes, that is fact. However, my family doesn't mind his autism. We already cope with him very well.

(Case 8, Reviewing session)

All the children experienced stereotyping and stigmatizing reactions, but were not prevented from participating in wider society. All the children in this study participated in social activities, daily routines and social circles with and without their autistic

siblings. These were commonly described or shown in their video diaries and home movies and included sports, shopping, dining out, family outings, playing (visiting) with friends, and after school clubs. D1 (Case 4) showed through her home movie that her daily routines with the family were not restricted (Figure 7-8)

**Figure 7-8** Shopping with Family (Case 4, home movie 1-5, time lap 00:02)



In the reviewing session, D1 explained that her family went out shopping or for a walk every night, and she had become used to people staring strangely at her autistic brother.

In another example, E1 (Case 5) also described routines with extended family members:

I visited my aunt's house at lunch time today. I played a computer game there. ....  
And [my family with] E2 and my aunt's family went to a department store to buy many items. Then, we had a delicious meal at a refurbished Korean restaurant.

(Case 5, video diary 5)

Although it was not guaranteed that social activities would always be successful, because of the unpredictable nature of autism, the children were able to join in social activities with the support of their parents. For example, D1 (Case 4):

**D1:** I went to a music concert. Piano and other musical instruments  
**Interviewer:** Did you go with D2 [her autistic brother]?

**D1:** Yes, but he could not go in there. I went in there with Dad.

**Interviewer:** What did your Mum and D2 do?

**D1:** Mum stayed outside with D2. (Case 4, reviewing session)

In another example, C1 (Case 3) described his social activities with his friends:

**Interviewer:** You said before that because of your older brother, you could not often go out or play with friends. Do you feel your life is restricted and limited in terms of time and place?

**C1:** No, I don't think so.

..... If friends ask to play, I sometimes play with them. Sometimes, I don't want to go, I would rather stay at home. Once we were in year 6, my friends were busy studying at home. We no longer played in the play ground at school - we liked to go to amusement parks. We arranged the date and time one week before, so if I told Mum about my plans, she arranged it so I could go

(Case 3, reviewing session)

These examples suggest that parents' flexible strategies for their children allowed them to participate in various social activities and integrate into social life. Moreover, all the children in my study also joined in various social circles such as after school clubs, sport clubs or private institutes for after school study '*hakwon*'. For example:

I go to a sports club once a week. I learn many physical exercises. I like sports club. I go there every Sunday. And tomorrow, even though it's Friday, I will be at the sports club at 9:00(am). I will practice basketball with my team members to prepare for a competition. I will have a friendly match.....I like to play basketball with my friends.

(Case 9, video diary 5)

Today, I went to club activities. .... I joined in bakery and cooking club. I made a cake there. It was the first time I made a cake. But my cake was not good. My mum praised my cake, and told me 'it is really good, you may open a bakery shop'. After club activities, I went to '*hakwon*', and I have just come back now.

(Case 1, video diary 8)

In terms of friendship, although the children in this study were concerned about friendships with peers, it did not mean that their peer relationships were limited. They all described good relationships with friends:

I have many friends, around 30 or 40 friends. (Case 8, reviewing session)

Today was the last day of the charity fair. Mum gave me 10,000 won. I bought a book for 8,800 won. I also spent 1,000 won to buy a snack for my friend.....then I also helped to clean my classroom<sup>53</sup> so I could come home with my friends.

(Case 5, video diary 3)

In this section I have shown how the children's lives revolve around the challenges associated with their siblings' autism where prejudice and negative stereotypes lead to strong feelings of stigma in public settings. At the same time their lives revolve within supportive structures created by those closer to them (parents, extended family and friends, as well as teachers and neighbours). It is these supportive structures that enable the children to participate effectively in wider social activities of daily life.

### 7.3.2. *Linking the 'Familiar' and the 'Strange'*

Within the home, the children in the sample experienced their autistic siblings' behaviour as familiar and part of ordinary everyday life. Outside the home environment, however, the negative reactions of the public to the behaviours of their autistic siblings led to feelings of stigma and shame. In chapter three, I introduced the concept of *Chemyon* (social face) an omnipresent feature of Korean daily life (Choi & Lee, 2002). The six oldest children in this study used the word '*jjockpalida*'<sup>54</sup> (a slang expression used by young people to mean losing face) when their autistic sibling behaved in a way that attracts attention in public. In this sense, the familiarity of living with an autistic sibling at home is thrown into sharp relief and becomes 'strange' (see Harwood, 2006). All the children in the study consistently experienced the explicit gaze of strangers

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<sup>53</sup> In Korean schools there is no tradition of employing cleaners. Classroom cleaning is undertaken by the children on a rota basis.

<sup>54</sup> The concept of '*jjockpalida*' indicates how the children lose face within their group or community.



towards their autistic sibling and the family. A1 and J1 described being 'stared at' when they were out with their autistic brothers:

**Interviewer:** What would you like to do if you could do anything with your family?

**A1:** Well... just walk on the street without people staring.  
I want to go Sin-Se-Kye Department store, E-mart supermarket [like other people]

**Interviewer:** What do you when people stare at you?

**A1:** [I get] really upset.

(Case 1, reviewing session)

**Interviewer:** Do you think [J2's] behaviour seems strange if he is in a crowded place?

**J1:** Yes

**Interviewer:** What do people do?

**J1:** Stare at him. He shouts in the subway.

**Interviewer:** What do you do?

**J1:** I don't do anything, I just let him do it.

**Interviewer:** What do you mean 'let him do it'?

**J1:** Well, I just pretend I'm not his brother

(Case 9, reviewing session)

These comments indicate that the children have become used to the way in which behaviour associated with their siblings' autism is perceived as 'strange' by members of the public. However, the unpredictable and unexpected behaviours associated with autism presented particular challenges in this sense as the following examples from J1 and G1 illustrate:

**Interviewer:** Now, where did he [J2] go on Saturday?

**J1:** Climbing

**Interviewer:** By himself?

**J1:** No

**Interviewer:** Who went with him?

**J1:** There is recreational session in his special school. He went to the mountain with volunteers.

**Interviewer:** According to your video diary, you said that J2 was very hard to control there.

**J1:** Yes. Last time, he soiled himself, but he does not at home.

(Case 9, reviewing session)

He made me *jjockpalida* [lose face]. Last time, we went the department store with G2. Mum asked me to look after him. I was waiting for her with G2 who was in a shopping trolley. But Mum did not come soon and G2 suddenly jumped out of the trolley and was going around with a loud voice. People tried to catch him. I was really embarrassed.

(Case 7, reviewing session)

These findings suggested that autism is an enigmatic disability that is not visible through the person, but only through their behaviour. The immediate invisibility of autism means that social expectations are constructed around ideas of socially acceptable behaviour. Autistic children are not as easily recognized or understood as physically disabled children, and their 'different' behaviours and forms of communication are widely interpreted as being problematic. 'Visibility' plays an important role in constructing cultural understandings of disability (Titchkosky, 2003:16). The visibility of autism, however, is unpredictable and the siblings of autistic children experience sharp and sudden transitions in the reactions of individuals as they show, through their gaze, the perceived 'strangeness' of their autistic siblings' behaviour, and the associated construction of the whole family as 'strange'.

While the children became used to being the subject of negative attention in public, six of nine the children (Cases 3, 4, 5, 6, 8 and 9) described experiences of positive social inclusion in public settings. For example:

**Interviewer:** Have you and your brother been teased or experienced discrimination by people?

**J1:** No, we have not. People say he is really cute. They normally respond to him very well.

(Case 9, reviewing session)

We often have a meal at a restaurant. People did not look at him strangely....He never makes me embarrassed in public.....My brother [C2] follows Mum silently. He has no problem, People may not expect [he is autistic]

(Case 3, reviewing session)

The children and their autistic siblings were typically involved in various interactions with people within and outside the family on a daily basis. And with their understanding of 'able-bodied' and 'disabled' society, the children experience the behaviours of their autistic siblings as 'familiar'.

Moreover, two of the children expressed a desire to inform public understanding of the realities of living with autism. For example:

When the English teacher read his textbook, he used horrible words to refer to disabled people. His words were really terrible. Then, my friends and I tried to correct his words 'no teacher, you must say disabled people'. But he said 'I don't care'.

(Case 1, reviewing session)

I want to change dramatically people's negative thoughts and misunderstandings about autism.

(Case 9, reviewing session)

These two children's desire to reframe the 'strange' as 'familiar' is linked with a desire to integrate understandings of autism as part of ordinary life. None of the children in this study called their autistic siblings 'autistic' or 'disabled'. For them, autism was less 'strange' and more 'familiar'. For instance, as H1 (Case 8) said:

H2, when I knew he was autistic, it was really hard, there were lots of hard things. But now, I am accustomed to him in daily life. I don't see it as strange, I am really wondering whether I feel it is hard

(Case 8, video diary-1)

Unlike other people, I do not regard 'strange' things as strange at all because I have adjusted already

(Case 8, reviewing session)

Here, we see H1's experience of autism as normal and a familiar part of ordinary daily life. But in the wider society, my findings indicate that autism may be experienced as strange and unfamiliar. I have used the perspective of 'familiar' to construct children's perceptions of ordinariness of living with autistic siblings in the wider community. The children do not emphasize the outward signs of autism, rather they focus on the reframing process that is consistently constructing ordinariness in their everyday lives.

### 7.3.3. *Understanding Autism*

The children's ability to integrate their siblings' autism as part of ordinary everyday life gives rise to the question: how do they understand and explain autism. All the children in the study use a 'medical' lens, to conceptualize autism. Their accounts referred to 'sickness' or 'illness' linked to brain abnormality, deficits of communication, and/or inappropriate behaviours. The following three examples illustrate children's understandings.

- G1:** My brother is seriously ill.  
**Interviewer:** What do you mean G2 is ill?  
**G1:** I don't know.....  
**Interviewer:** Do you know what 'disabled' means?  
**G1:** His head

(Case 7, reviewing session)

- Interviewer:** In your video diary, you said 'my brother is ill now'?  
**B1:** Yes, his head [is not well]  
**Interviewer:** Head?  
**B1:** That's what mum told me

(Case 2, reviewing session)

- Interviewer:** Do you know about autism?  
**C1:** It means you cannot communicate with others.

(Case 3, reviewing session)

J1 (Case 9) used a special term '*maljit*', to describe autism referring to behavioural characteristics;

- Interviewer:** You said *maljit*. What is that?
- J1:** Yes, *maljit*. For example, he picked up vegetables or tore newspapers in his room while mum was out.
- Interviewer:** Is it your word?
- J1:** No, everyone uses the word.
- Interviewer:** Everyone says it?
- J1:** It's like mischief
- Interviewer:** Is that what it means?
- J1:** Yes, it means being naughty.

(Case 9, reviewing session)

Seven of the nine children linked these characteristics and believed that the limitations of autism could be overcome<sup>55</sup>. In this way, they reframed autism within a medical perspective and saw autism as an illness from which their autistic siblings would be cured (see section 6.2.2). These children's views of autism are contrary to wider cultural understandings of autism as being a long term, disabling condition. In the home movies, five of the nine children (Case 1, 3, 4, 8 and 9) focused more on their autistic siblings' **abilities** (see Figure 7-9):

**Figure 7-9** A2 Cleaning Living Room (Case 1, home movie-2, time lap 00:19)



<sup>55</sup> The two exceptions were younger children who did not engage with explanations for their siblings' autism.

In this way their autistic siblings were not primarily seen as autistic (see chapter 6), although the children did not deny their siblings' autism. Rather they focused on overcoming impairment. As a result, the children were very proud of their siblings' determined efforts and achievements. For example:

Honestly, if a disabled child has done well, s/he has really worked very hard.

(Case 8, reviewing session)

J2 gets more good marks than children without disability. I am very proud of him.

(Case 9, video diary 4)

C1 (Case 3) describes a more complex achievement:

One time, my brother disappeared. We looked for him from dawn to mid-night but we couldn't find him. I went home, then someone phoned me. He told me that he was with my brother. My brother told him our home phone number. I asked where they were. I phoned Dad immediately and he took him home. Next day he disappeared again. We informed the police station. ....I didn't know how he could get home. Anyway, he came home at 1:00am by himself.

(Case 3, reviewing session)

Importantly, two of the nine children (Case 8 and 9) described their autistic siblings' potential to achieve an independent life in future:

Well, to be honest, people with disability are not so different. People assume that there are big differences between disabled and normally developing children. So in the beginning, it was expected that parents should take care of disabled children until they died. Therefore, people assumed that it could be very hard. But, honestly, it is not. If disabled children are disciplined well, disciplined in verbal language, they can speak very well and can communicate. It is possible. Then, they can marry. If they get taught well, they can communicate when they grow up. Moreover, they are more attractive if they are handsome. So I don't worry about him. Mum, Dad and I believe strongly he will fall in love with a good girl, marry her and live long time.

(Case 8, video diary-12)

Like other autistic people, I believe that he will get a job and earn money. I believe he will live independently

(Case 9, reviewing session)

Thinking about the likelihood of their autistic siblings having children of their own, the six oldest children<sup>56</sup> believed that autism did not carry the risk of genetic inheritance:

**H1:** An autistic person can get married and can give birth to a normal baby.

**Interviewer:** Why?

**H1:** Autism might not be related to genes, rather like a person with physical disability who uses a crutch can marry and give birth to a normally developing baby. .... It is not a genetically inherited condition. It is very lucky that autism is not transmitted through genes. If autism could be inherited, if they got married, they would probably be concerned about the children, so they cannot marry. It is not genetic, thankfully it is not.

(Case 8, reviewing session)

In summary, despite their experience of the wider public's stigmatizing views of autism, seven children did not identify autism as a tragic life-sentence but reframed their understanding of autism as 'ordinary' or 'able to do', even 'curable', so that they believed that their autistic siblings could be integrated into and, in the case of two children, live independently within wider society. Although all the children have experienced the limitations surrounding autism, they all emphasize their autistic siblings' abilities and strengths rather than the deficits associated with autism. What is remarkable about their perceptions and understanding of autism and its implications is that they were conveyed against a background of culturally embedded negative public representations of disability in Korea.

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<sup>56</sup> The three youngest children were not asked about genetic inheritance. Evidence suggests that children aged eight and below are unlikely to have sufficient understanding (e.g. Gallo *et al.*, 2005)

#### 7.4. Parents' Views of Their Normally Developing Children's Daily Lives in the Family and Wider Society

All the parents (nine mothers and two fathers) in this study invested most of their attention, energy, time and money in the treatment or education of their autistic children, leaving little time, and less attention, for their normally developing children. Part of the reason for this is their common belief that if their autistic children receive proper treatment, they will become an 'ordinary' child like other children (e.g. Grinker, 2007).

**Mother:** Yes, well, if he [G2] did not have autism, like a normal child, I would pay the same amount of attention to all my children. But he [G2] needs more attention because of his disability, so I inevitably pay more attention to him. I suggested to my husband that special education for G2 should be arranged until he was 10 years-old, year-3 - around year-3 or 4. If it is not effective, if we reach the bottom, we will pay for one or two support services for him. I told my husband. We might regret it if we don't get support [for G2], we might feel less regret if he gets treatment or education by that age. So I suggested to my husband that we were willing to offer these services up to age 10 or 11, even though we would pay a lot of money.

**Interviewer:** Why around aged 10 or 11?

**Mother:** Generally, nearly all parents would like to stop special education for cognitive development or language by around that age. In other words, until a child becomes age 10-11, they would receive lots of treatment or education. [Parents] realize that their children may not be able to improve. So, nearly all autistic children would stop treatment or special education.

(Case 7, G1's mother)

All the parents explained that giving priority to their autistic child exacerbated their limited capacity to meet the needs of their normally developing children. For example:



I was willing to sell our house to pay special treatments for him [B2]. I took him to here, I took him there, everyday. I was really busy. At that time, B1 said to me 'Mum, your mind is full of my brother'.

(Case 2, B1's mother)

The normally developing children were largely left to make their daily life by themselves:

**Mother:** She had a positive personality. But she has found it very hard for a long time.

**Father:** Because she rarely got her mother's attention. Mum always was busy looking after her brother. Dad was always busy at work. She stayed alone and may have felt neglected.

(Case 1, A1's parents)

In this way the siblings became the 'forgotten children' (Seligman, 1999:126; Van Riper, 2003: 282; van den Hoed-Heerschop, 2007:113) within the family context. J1's mother (Case 9) explained:

I am always thinking about J2, but I do not think too much about J1.

And A1's mother simply stated:

I did not remember how A1 grew up.

(Case 1, A1's mother)

This superficial engagement with their normally developing children meant that the parents in this study did not have a deep knowledge of their normally developing children's perceptions of their family life. Despite various challenges experienced by the normally developing children, the parents in this study argued that the family context of living with autistic children did not always have negative consequences for their normally developing children. All the parents in the study tried to compensate their normally developing children for the lack of time they spent with them and for the alterations and limitations to their daily life, which resulted from having a child with

autism. For example, J1's mother, describing how they sent him to the United States commented:

I don't think J1 has been treated differently. .... Honestly, it was excessive. We had to pay 3,000,000 or 4,000,000 won (approximately £1500-2000). Although we did not pay accommodation fees, we had to pay for the flight and summer camp. We considered carefully but I discussed deeply with J1 regarding this. An amount of money had been paid for J2 and I said to J1 'we would also like to pay for you'. We will send you [to the United States]. Therefore, he was sent to the United States twice. As a result, I would like to think he did not feel unfairness.

(Case 9, J1's mother)

The parents expected their normally developing children to mature earlier and to accept the loss of opportunities available in 'ordinary families'. Moreover, all the parents expected that the normally developing children should accept responsibility for helping them and helping their autistic siblings. For instance, J1's mother said:

My husband was really busy. Without his help I was left to take care of the children. I probably relied too much on J1. I expected that he [J1] could understand me. While he looked after his brother, I could have a shower or bath.

(Case 9, J1's mother)

The parents realized that their normally developing children felt a significant care burden, even if it was temporary:

Our [my] daughter's smile was really beautiful but I could not see her smiling face everyday. Honestly, she smiled so as to hide her feelings. Through her eyes, she said 'Mum, I am alright' because she saw me struggling terribly to cope with D2. .... Even for 10-20 minutes, D1 felt the obligation to look after D2..... I felt sorry, I realized how she felt the amount of this burden.

(Case 4, D1's mother)

Nevertheless, all the parents believed that if their normally developing children did not make sacrifices in their childhood and current daily life, they (the parents) would have

been faced with unmanageable care hardships. Therefore, the parents relied consistently on their normally developing children's contribution to caregiving.

All parents in this study had little awareness of their normally developing children's lives in the wider community. A good example is offered by J1's mother who, after reading his diary and discussion with his teacher, discovered difficulties he was having at school and in making friends:

I was shocked. I did not know how much he felt hardships [at school and with friends].

(Case 9, J1's mother)

H1's mother also learned about some of H1's experiences from talking with her teacher:

I thought she did not have any trouble [with friends in school] but she had, I really do not know [her life at school] now.

(Case 8, H1's mother)

None of the parents knew how their normally developing children got on in the wider community. But they did comment on their inability to protect them from stereotypical reactions in public. Seven parents (Case 1, 2, 4, 5, 6, 7 and 8) referred to the vulnerability of their normally developing children in wider society, associated with the 'stigma' of being from a 'disabled family'. One mother illustrated a crucial aspect of stigma:

He is growing up now, nevertheless, sometimes, he struggles ..... there are lots of people who don't understand my child [E2] while I take him out in public. They treat us as strange [mad]. I am really worried about this.

(Case 5, E1's mother)

E1's mother was worried that the powerful influence of socio-cultural attitudes to disability may be enough to reinforce his sense of being different and undermine his sense of ordinariness in everyday social and community life. An illustration of this point is that all parents knew that their normally developing children did not like talking about their autistic siblings to others. For example, B1's mother said:

She might recognize [abnormality of autism], but never mention her brother's verbal impairment. ....she does not want to talk about her brother outside the family. (Case 2, B1's mother)

Five parents (Cases 1, 2, 4, 5, and 6) pointed out that their normally developing children were distressed by the dehumanizing terminology (e.g. *Babo* (dummy), *Michin* (Mad, Crazy)). On the other hand, one parent reported how she used a strategy of positive reinforcement to help her normally developing child elicit positive responses towards the stereotyped reactions. D1's mother (Case 4) illustrated this strategy:

Twins who live in same apartment were in the same class as my daughter last year, But they are not in the same class this year. When they came to play in my house, one said *babo* to D2. My daughter heard what he said. Other friends called me and said, 'PF said *babo* to D2'. At the time I saw D1's face. She was not happy at all.

D1's mother then called PF and used word play to help PF have a better understanding of autism and to help D1 not to feel defeated by the use of such language and how to educate others who use such terms. She went on:

..... I really did not know how my daughter felt. But she played with them the next day. .... The word '*babo*' I did not want D2 to be called that. So I used word play skills to make a joke. Nevertheless, I did not really know what she thought about my strategy. (Case 4, D1's mother)

D1's mother believed that her positive way of responding to the negative socio-cultural value placed on disability could be a positive influence on D1's daily life outside the family. This finding suggests a clear role for parents in empowering their normally developing children to develop skills of self-advocacy in challenging negative cultural norms and changing perceptions of disability.

Overall, the parents' contributions to this study illustrated both the particular challenges and ordinary lives of their normally developing children in the wider community and

society. Strikingly, they had little knowledge of their normally developing children's experiences and perceptions of daily life within and beyond the family. It seems that parents were not unwilling to help their normally developing children develop strategies for dealing with the challenges of everyday life outside the family. The opportunities for such help however depended on prior awareness of their children's challenging experiences, and it was this awareness that was lacking as parents focused their attentions on their autistic children, rendering their normally developing siblings 'invisible'.

### **7.5. Summary**

In this chapter, I have used children's accounts, supplemented by their parents' accounts, to explore their experiences of autism and the ways in which they construct and reconstruct their daily lives as ordinary within the family and wider society.

The children's accounts offered evidence of: i) ordinariness, in which adjustments to family life are made without conscious thought, ii) awareness of their siblings' autism, and iii) the practical and social challenges this brings. Parents' attention, time and resources were compromised with less being available for their normally developing children whose needs took second place to those of their autistic siblings, a theme on which I focus in the next chapter.

The children accepted a shift of centrality giving respect and love to their autistic siblings as well as their parents. In wider society, the children experienced a number of cultural barriers to social inclusion, in particular the stigma associated with having an autistic sibling. As a result, some families in this study kept their autistic child largely hidden from neighbours and the public. However, the children's accounts of autism focused predominantly on 'ability' and 'strengths' rather than 'deficits', although they often faced an unstable situation and complexity within a predominant cultural discourse that devalues disabled people. In particular, the concept of autism as 'curable illness' reframes autistic children as having value and positive potential. Through the

interaction process of 'linking the familiar and the strange', the children achieved ordinariness in shaping their lives despite the presence of an autistic sibling.

The children in this study confronted a dynamic of two worlds characterized by the 'difference' associated with autism and the 'ordinariness' of everyday living. Although the children knew that their autistic siblings did not meet accepted sociocultural standards, merging the familiar and unfamiliar views of their autistic siblings allowed them to construct an ordinariness in their everyday lives. Striving for ordinariness appeared to help the children to reconstruct a sense of balance in their lives within the family and wider society. In the next chapter, I focus on the aspects of the children's lives that may be constructed as 'hidden costs of cultural value and expectation'.

## **Chapter Eight**

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# **The Vulnerability of the Siblings of Autistic Children**

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## 8.1. Introduction

In the previous chapter I focused on the processes by which the children achieved a sense of balance in their lives, integrating the ‘different’ experiences of living with an autistic sibling into ordinary everyday experiences in order to achieve a sense of ‘sameness’. But I argue that their significant achievements in making sense of their situations as children with autistic siblings mask their ‘vulnerability’<sup>57</sup>. I further argue that this process of masking is so effective that the ordinariness they achieve in their daily lives is easily ‘taken for granted’ by their parents. More widely, their contributions to the care and well-being of their autistic siblings may be unknown to the wider community and society since their relative lack of recognition within the family is reinforced outside the family by cultural norms that equate disability with shame. It is in this sense that I address what I have termed vulnerability. It is important to note that ‘vulnerability’ represents the themes derived from the children’s video diaries, home movies and reviewing sessions, as well as interviews with their parents. These themes include voicelessness, hierarchical position, inattention, poor information, impact on school work, lack of safe space and financial resources. A final theme, relating to collective forms of social support, was derived from discussions of ‘voicelessness’ during reviewing sessions. In this chapter, I explore each of these themes in turn.

## 8.2. Understanding the Vulnerability of the Siblings of Autistic Children

### 8.2.1. *Voicelessness*

In this study, the most striking aspect of the children’s vulnerability was their voicelessness. None of the children in the sample readily expressed their own needs, or

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<sup>57</sup> In this thesis, vulnerability refers to threats to well being arising from the implications of the presence of autism in the family. These include shame associated with disability and humiliation associated with (relative) poverty that often results from the higher financial costs to the family of caring for a disabled child. In order to maintain family honour and family harmony the non-disabled siblings conceal the threats to their own well being.



made demands. For example, after discussing their autistic siblings' need for help I asked the children about their own needs:

- Interviewer:** Do you think you need help?  
**C1:** No, I don't need anything. (Case 3, reviewing session)
- Interviewer:** Do you need any help?  
**E1:** Not at all (Case 5, reviewing session)
- Interviewer:** Do you think you need help.....  
**H1:** No, I don't need any help.  
**Interviewer:** Really? Why?  
**H1:** I can do everything by myself  
(Case 8, reviewing session)
- Interviewer:** Do you need any help?  
**J1:** No [I don't need], we [my family and I] can do ourselves  
(Case 9, reviewing session)

The children did not perceive themselves as being vulnerable in the sense of needing help. They identified themselves as 'healthy children', not as 'children affected by their autistic sibling'. There is now increasing recognition of children as active agents, who develop their own strategies for coping with adversity. However, Hutchby & Moran-Ellis (1998) argue that children's competencies vary with context and coexist with their biological vulnerabilities and relative lack of experience. Moreover, it can be argued that the new sociology of childhood itself reflects some cultural contexts (European and North American) more than others (Mayall, 1994; Jenks, 1996). It is therefore important to highlight specific cultural differences that may have some bearing on the interpretation of the children's competency (see for review Gladstone *et al.*, 2006). For example, Wong (2004:104) comments that 'since Confucian teaching emphasises humility and self-discipline, positive view of self and effectiveness (as presenting in resilient children) would be identified primarily by confidence in that individual's action rather than verbal report, as the latter would appear vain and conceited in Confucian society.'

In Korean communication, the use of 'yes' and 'no' signifies more than simple positive and negative responses. In this sense, 'yes' does not always necessarily mean 'yes', and 'no' does not always necessarily mean 'no' since each word may be used to indicate deference, to highlight honourable acts and conceal shameful situations – most closely translated in Western terms as denial. It can, therefore, be difficult to get at the truth of intentions. Unhappiness and disagreement are often hidden in phrases such as 'it's OK' or 'I'm fine'. For example, Kim, Y. (2002) showed that young Korean adults have a strong tendency to hide problems (e.g. disability, health problems), particularly from those outside the family, due to heightened sensitivity in matters of honour and shame.

The advantages offered by membership of the same cultural group in undertaking this research contrasted with the challenges I faced in achieving depth of information and understanding from the children and their parents with whom I was expected to respect cultural codes that inform behaviour between family members – and visitors to the family home. The children's diaries and movies allowed for free expression but in both elicitation sessions with the children and interviews with the parents it was necessary to employ techniques of gentle probing to extricate more meaning from what were sometimes, at first, brief and unrevealing responses. The emphasis was on creating confidence in the children and their parents to be able to express their feelings free of shame in my presence, not on encouraging responses that fitted with any preconceived notion of what I wanted to hear, or expected them to say. As Byrne (2004:183) argues: 'interviews are often analysed both for what interviewees say about their lives and experiences and for how the information is communicated and the accounts are told'.

In this sense, it is possibly argued that the outward appearance of increasing independence and positive adjustment to their autistic siblings does not mean that the children did not face vulnerability. In a reviewing session, H1 (Case 8) illustrated her own circumstances:

**H1:** Honestly, I cannot talk about me and my family to people, even Mum and Dad. Although I can talk to Mum and Dad, it is very shameful if I do. So, I am proud of myself, that I can bear any of the hardest things about my brother's behaviours. That is

how I want to show myself to others. However, alone, I cannot do anything, but I want to show..... but I am sad because I cannot. I have never talked honestly to anyone about my thoughts because I do not want to. Sometimes, it would be good to talk with someone when I cannot bear the situation, but I can't because of my stubbornness.

**Interviewer:** Never?

**H1:** Never, .....

I don't want to let my Mum or Dad know how I really feel.

I take pride in myself who can bear my brother's impairments, but Mum and Dad cannot. If I tell my story to Mum and Dad, I would lose my pride. [they will feel] 'oh, indeed, she cannot overcome', although Mum and Dad would not like to talk directly. Therefore, it would be better to talk to friends, but they do not understand.

H1's account captured the voicelessness of the children in this study who were reluctant to express their own needs to others, especially their parents. The children often used an alternative way of expressing their thoughts and feelings that involved hiding their vulnerability to meet the cultural expectations associated with being a good sibling. Similar experiences of hiding vulnerability were also described in Cases 1, 4, and 9

Voicelessness was also apparent through parental rejection. For example, in the reviewing session with G1 (Case 7), he complained about always having to clean and tidy up after his autistic brother. I asked why he felt unable to speak to his mother about this.

**G1:** I was scolded severely by Mum when I told her. It was the first time [experience].

**Interviewer:** What did you say to Mum?

**G1:** I asked, why do I have to tidy up the mess that was made by G2?

**Interviewer:** What did your Mum say?

**G1:** [Mum said] Because you're the older brother

(Case 7, reviewing session)

This episode represents a form of rejection in which the child's voice was silenced and his feelings denied. This experience of being silenced by parental reactions was also described in Cases 1, 3, 5, and 9

To summarize, the data indicate indirect and direct silencing of the children who respond to internal (self silencing) as well as external forms of 'discipline' and control by their parents. These findings therefore suggest that any effort to respond to the needs of siblings of autistic children must be supported by a deeper and broader awareness of their vulnerability through 'voicelessness'.

### **8.2.2. Hierarchical Position**

Taking and accepting second place was a feature of everyday family life for the children (see section 7.2.2). They learned to place their autistic siblings' needs before their own. In a context of Confucian familism, individuals' needs are sublimated to the higher need to demonstrate interdependence and family harmony (Fitness & Duffield, 2004:481). The individual vulnerability of the children in this study was exacerbated by the suppression of their own needs, taking 'second place' to their autistic siblings. In a reviewing session, for example, G1 (Case 7) described his relegation to second place:

- G1:** My brother is the first. Everything, he is given the first.
- Interviewer:** How do you feel about that?
- G1:** Sometimes, I complain. I feel annoyed, I am the older brother but Mum always says, 'you, as an older brother, must understand' (Case 7, reviewing session)

In the family context, G1's account offers an example of children facing the dilemma of reconciling recognition of their own priority and the high level of priority given to their autistic siblings. All parents in this study referred to the lower priority they gave their normally developing children, as illustrated by C1 (Case 3)'s mother:

While my children were growing up, the eldest, especially, when she was in kindergarten, elementary and middle school, she needed a lot of help from us, [but I couldn't help] most days, I was somewhere with C2 whenever the other

children came back from *hakwon*. They were hardly handled by me at the time of elementary and middle school. As a result, they could not study and manage their lives well.

(Case 3, C1's mother)

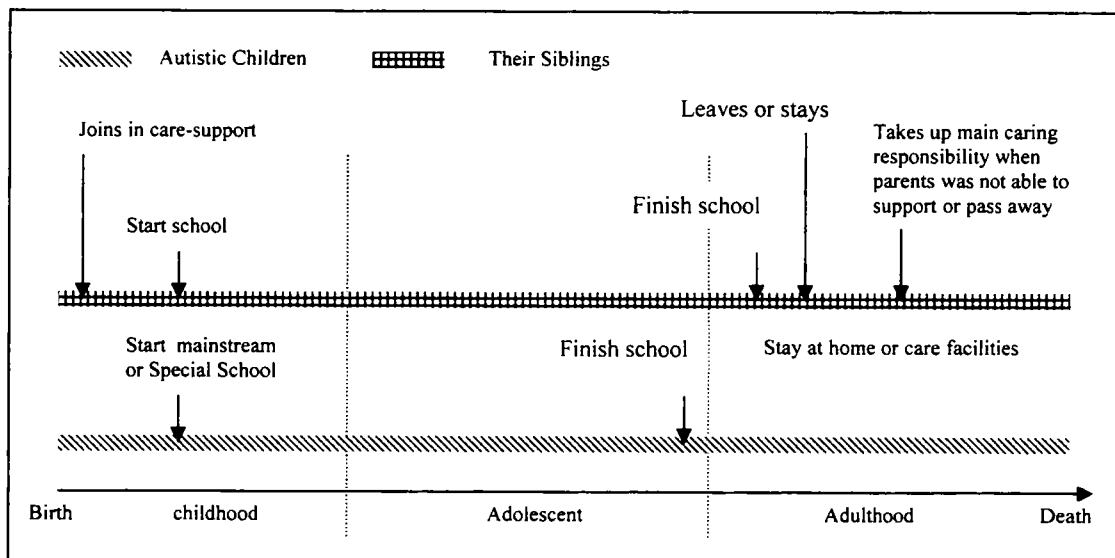
This mother's account shows how lower priority within the family can contribute directly to vulnerability in their normally developing children's current and future lives. This vulnerability, however, is not easy to recognize since it is hidden behind the more obvious vulnerability of their autistic siblings. This finding suggests that any possibility of responding to the needs of children with autistic siblings will require prior recognition of their needs and commitment to equitable treatment.

### 8.3. Other 'Suppressive' practices

#### 8.3.1. Parental Inattention

I have shown earlier how all the children in the study were expected to help their autistic siblings, with general and intimate care (e.g. playing, feeding, supervising (i.e. washing and brushing)) and with household chores. They formed part of the care support system in the family from an early age (see Figure 8-1). This is illustrated in Figure 8-1.

**Figure 8-1** Life Timelines of Children and Their Autistic Siblings



In chapter 7, I argued that children with disabled siblings are expected to be more 'mature', and self managing than children of similar ages without disabled siblings. The children in my study described different ways in which they received low levels of parental attention and care from their parents. For example:

**G1:** At 7 o'clock, when I went to *gongbu-bang* [kind of *hakwon*]  
I cooked food for dinner by myself .....

**Interviewer:** Did you say you cooked dinner by yourself?

**G1:** Yes

**Interviewer:** Were you all right [cooking by yourself]?

**G1:** I don't mind

**Interviewer:** Don't mind?

**G1:** Sometime it's ok, but sometimes,

**Interviewer:** You mean 'you don't like it' sometimes?

**G1:** When I have stayed alone

**Interviewer:** Do you often stay alone at home?

**G1:** Yes

(Case 7, aged 12, older brother, reviewing session)

**Interviewer:** Did you say you have often stayed alone at home during  
the last year?

**E1:** Yes

**Interviewer:** When you stay at home alone what do you do?

**E1:** Homework, computer, watching TV and so on

**Interviewer:** Do you feel all right without Mum?

**E1:** Yes

**Interviewer:** How did you feel?

**E1:** As usual, I'm already used to staying alone.

**Interviewer:** If you need Mum and Dad, what do you do?

**E1:** Just phone them

(Case 5, reviewing session)

**C1:** Yes, it is difficult to play with friends now. It also is not easy to  
play with my brother outside the house. I'm bored when I stay  
alone at home.

**Interviewer:** Have you often stayed alone at home?

- C1:** Definitely yes  
**Interviewer:** What did you do alone?  
**C1:** Computer, studying...

(Case 3, reviewing session)

All the children have experiences of being left alone, in terms of parental presence or parental support, and indicated feelings of loneliness, boredom, insecurity and anxiety in such situations.

Two mothers (Case 1 and 7) also described their normally developing children's sense of insecurity. A1 (aged 15)'s mother explained:

- Mother:** I think she [A1] was never spoilt. But I don't remember how I brought her up.  
**Interviewer:** Who brought her up?  
**Mother:** Generally, I took her to *noribang* [day-care centre] every morning, and took her to her grandfather after *noribang*.  
**Interviewer:** Did she miss Mum and Dad?  
**Mother:** Absolutely yes, whenever I took her to *noribang*, she stuck to me and cried too much. I also cried.

(Case 1, A1's mother)

And G1 (aged 12)'s mother talked of her expectations that G1 be self managing:

In my view, he should do more. In other words, in my thinking, he is not disabled and in Year-5. So I hope he would like to look after himself. In other words, I actually expect him to do everything by himself. However, when he doesn't, I shout at him 'why can't you, you can do it' I get angry with him

(Case 7, G1's mother).

In the contemporary Korean family context, mothers carry the majority of child care responsibilities, with fathers' involvement being restricted to play with children when they have the opportunity (Lee, K.K., 1998:257). In my study, reduced maternal attention for the siblings of autistic children was perceived as inevitable by the mothers. Moreover, all the children in the sample were expected to cope with receiving less

attention and less support, so that they were largely left to manage their own daily activities. Unlike children in homes where there are no disabled children, the children in my study were expected to go to and from school on their own, to cook some meals, attend appointments with the GP alone, and generally expected to take a higher level of responsibility for their own lives as well as those of their siblings.

An understanding of their vulnerability depends upon an understanding of the ways in which caregiver and care-receiver roles become blurred so that their positions as 'children' and their positions as 'responsible sibling' lose their distinctiveness. In this way, less parental attention and greater caring (and self caring) responsibility become part of the normative expectations associated with filial obligation, but also serve to conceal the children's vulnerabilities.

### **8.3.2. Information**

Although autism does not fit a single or typical pattern of impairment and has a range of symptoms (Harris, 1994; Powell & Gallagher, 2005) this study finds that: i) lack of information about autism, or how or where to access this, are concerns among the siblings who relied on their parents for information, ii) a single example of information that was not derived from parents involved misinformation (possibly based on confused understanding from health education in school), and iii) parents are reluctant to talk to their normally developing children about their siblings' autism.

A reviewing session with J1 illustrates poor knowledge about the specific characteristics of autism:

- Interviewer:** Do you know what autism is?  
**J1:** Yes  
**Interviewer:** Please tell me what is autism?  
**J1:** Autism might be that someone cannot speak, cannot learn whatever they are taught, and have mental problems.  
**Interviewer:** Where did you get this information?  
**J1:** I discussed with my Mum and Dad  
**Interviewer:** Have you received more specific information about your



- brother?
- J1:** No
- Interviewer:** Do you look for new information about your brother?
- J1:** [shakes his head indicating No]
- Interviewer:** Never? Why?
- J1:** I talked with my Mum several times.

(Case 9, reviewing session)

Although J1 associated autism with difficulties in speech and learning and ‘mental problems’, he had no knowledge about autism in general or his brother’s specific condition. The reviewing session (above) suggests that J1 had tried to seek information from his mother but had not sought information elsewhere. This sole reliance on parents for information was typical of the children in the sample and led, in some cases, to the children acquiring erroneous understanding.

In B1’s (Case 2, aged 7) reviewing session, she described her understanding of autism as ‘illness associated with brain’ ‘being unable to speak’ and told how her mother had explained that this inability to speak was the outcome of lack of attention:

- Interviewer:** Have you heard about autism?
- B1:** My brother is not well in the brain
- Interviewer:** Brain? Who told you about this?
- B1:** Mum told me.
- Interviewer:** Your Mum?
- B1:** My Mum told me. My brother could speak [when he was younger] but he cannot say anything now. Mum said
- Interviewer:** Did she tell you?
- B1:** Yes, my Mum said that she gave me more love, more praise [than my brother] so, my brother was not happy.....I heard from Mum. When I was baby, my brother could speak. He also rode a bicycle with me.

(Case 2, reviewing session)

In the one case where information about autism did not come directly from the parents,

H1 offered an explanation of autism as a genetically inherited disorder caused by smoking or drinking:

If people who smoke or drink alcohol have a baby it is like a mutant, not an ordinary baby. But my Mum and Dad never smoked or drank any alcohol, so I think it's unfair that H2 was born disabled. I wonder why H2 was born autistic. Honestly, [I don't know] how he is disabled, why he was born disabled, I really wonder what's wrong with them. [My parents] never smoked.....I question why H2 was born with a disability. Really, I wish he was not disabled. Honestly..... I really wonder why H2 was born disabled.

(Case 8, video diary-6)

When asked how she knew about the links between smoking and drinking and autism, she indicated that it was general knowledge: 'everyone knows'.

The two preceding accounts indicate that the children had misleading information and in H1's case, she was left wondering why her brother was autistic.

The children's attempts at understanding autism represent forms of 'rationalization' and indicate that they had not received information appropriate for their developmental stage. None of the children in the study received information directly from doctors or other professionals. And although all the children received information from their parents, the parents themselves declared their own lack of deep knowledge about autism. In the interview with H1 (Case 8)'s parents, for example:

**Interviewer:** Have you ever talked with H1 about autism?

**Father:** Well, not really talked about it. But I just said that autism is something like that. So you [H1] should understand more about him [H2]. At that time, even though we discussed autism, H1 may not have understood because she was young. So I just told her briefly [about autism].

**Mother:** We did not discuss with H1 in everyday life. But we discussed whatever I supposed that H1 may know about autism. I thought that she may listen when we [Mum and Dad] talked about what autism is, and how it is different from

being mentally retarded. I assumed that she may know how autism is different from Down's syndrome, being mentally retarded, or having cerebral palsy. But we never discussed deeply with her.

All parents experienced difficulty in discussing autism deeply with their normally developing children. For example, A1 (Case 1)'s father said:

A long time ago, I had a chance to talk with her about her brother. But I hadn't enough time to talk with her. She also said with smile, 'that's enough'. Then, she was not willing to talk further about it. I feel she may not want to talk about a sad story.....she is willing to talk about good things but she would not want to talk about a heartbreaking story. Yes, I assume. She may be concerned about us [Mum and Dad]. If we discussed, she may be concerned that Mum and Dad could be sad. She may try to avoid discussing this matter.

The issue of autism was not easily discussed within the family with the result that the children were not given clear information about their siblings' autism even by their parents. Even where the children had successfully adjusted to living with autism, this must not be mistaken for an indicator of the children's knowledge or understanding of autism.

Overall, knowledge and awareness of the condition of autism among the children was limited. The children and their parents did not often talk about autism or share information with each other.

### ***8.3.3. Impact on School Work***

As discussed in 5.5.3, one aspect of being a 'good sibling' involved successful educational achievement, reflecting the cultural value placed on academic success. The children in the sample were under additional pressure to achieve since their parents no longer expected successful educational achievement from their autistic children. The siblings were expected to obtain a promising and secure future for their autistic brother or sister and family by studying hard, since academic success is perceived as the path to

social success (e.g. Kim & Dembo, 2000; Yang & Retting, 2003), and higher social status can mitigate the negative social effects and social stereotypes associated with autism. In this way, the children's degree of academic achievement determines the status of their families in the community and wider society. The video diaries and home movies for seven of the nine children (Case 1, 3, 5, 6, 7, 8 and 9) depicted studying as a main part of their daily life (see Figure 8-2).

**Figure 8-2** Homework (Case 6, home movie-1, time lap 01:00)



Although the children knew about the importance of academic work, they struggled to keep up with their work, disturbed by their autistic siblings. In particular, two adolescent girls (Cases 1 and 8) in the study explained that they found it hard to study at home, since it did not offer a supportive environment. Six of the nine children (Case 1, 3, 4, 5, 7, and 9) also chose to tell or show how their educational materials (e.g. textbooks, computer, stationery) were often spoiled or destroyed by their autistic siblings. For example:

- E1:** Recently, my brother took items out of my school bag.  
**Interviewer:** Did he?  
**E1:** Yes, recently, for example, he took out my pencil case, pen, and textbook.

(Case 5, reviewing session)

A1 (Case 1) presented a similar story through her video diary and expanded in the reviewing session:

**Interviewer:** According to your video diary, you said you cried because your brother touched your belongings.

**A1:** At that time, I was watching TV for a few minutes.  
He came in my room and scribbled on my textbook.

**Interviewer:** So,

**A1:** Although I lock the door everyday, he opens ..... If my pencil has disappeared, I find he has it.

H1 (Case 8) pointed out the disadvantages of studying with her autistic brother at home:

So, I should receive a special benefit. Don't you need to study in a proper environment? But I cannot prepare examinations at home because my brother shouts, I cannot concentrate on study.

(Case 8, reviewing session)

H1's account indicates that disturbance caused by an autistic sibling can affect studying, especially in preparation for examinations. As a result, she felt she may not get good academic marks and may fall behind in academic work. In line with H1's account, C1 (Case 3)'s mother talked of her daughter's academic failure:

C3 [oldest daughter] has not been supported in her studies. She only went to *hakwon*. She couldn't get any private lessons. Honestly, I said 'you should study very hard. If you do, even though you go to *hakwon* only, you will be a success.' But she failed The National University Entrance Examination. She couldn't study deeply. Until middle school, she got very good marks. But when she was in high school, her marks went continually down ..... So she might need more support in her studies. .... I feel very sorry for her....I always worked with C2, but I never helped her study since she was in Elementary school. For example, I never worked with her for preparing spelling test

(Case 3, C1's mother)

C1's mother felt guilty for not adequately helping her daughter succeed in school and university entrance examination.

However, the children's academic performance did not always suffer directly as a result of living with an autistic sibling. Rather, living with an autistic sibling increased the children's vulnerability to academic failure creating a potential barrier to success in future life.

#### **8.3.4. Lack of 'Safe Personal Space'**

This study has shown that lack of personal time and disrupted privacy are very common daily experiences for the children, all of whom acknowledged that managing to spend uninterrupted time by themselves was very difficult. For example, H1 (case 8) and A1 (Case 1), adolescent sisters, indicated that they valued the chance to have undisrupted time and space for themselves:

**H1:** Well, it's secret. I'm honestly uncomfortable to sleep with H2.

It would be better to have my own room

**Interviewer:** So?

**H1:** I wish I could have my own room.

Honestly, it is uncomfortable to sleep together. Moreover I cannot study, I wish to watch TV [in my room]

**Interviewer:** Yes.

**H1:** I'm concerned about disturbing my brother's sleep....

So I cannot watch soaps

(Case 8, reviewing session)

Another finding was that A1 (Case 1) showed anger in relation to loss of her private space and she felt obliged to lock the door while she was in her room.

He always stays in my room. Mum said he comes out of my room whenever I come home. .... If I see he is in my room, I shout at him.....I always lock the door while I am in my room.

(Case 1, reviewing session)

A secure place and time for 'recharging' are very important for the children. Six children (Cases 1, 3, 4, 6, 8 and 9) used their video diaries and home movies to show that the home environment offered no space or time to escape from the disrupting behaviour of their autistic siblings. 'Recharging' is significantly related to personal safety and protection, particularly where their disabled siblings display aggressive behaviour (see e.g. Kendall, 1999). Although only one child (Case 6)'s home movie depicted aggressive behaviours of her autistic sister, forms of physical aggression were reported by a further four children (Cases 1, 6, 7 and 9). For example, A1 (Case 1)'s accounts centred on the issue of safety from the excessively aggressive behaviour of her autistic older brother:

**Interviewer:** [referring to incident in which the autistic child in the family hit her] As you know, I have experienced your brother's aggressive behaviours. Does he [A2] hit you?

**A1:** Sometimes

**Interviewer:** What do you do?

**A1:** Run away from him

(Case 1, reviewing session)

And J1 (Case 9) said:

**J1:** J2 often pinches Mum and me.

**Interviewer:** What do you do?

**J1:** Mum seriously scolds him but I have to accept it when he is upset. For example, he always gets perfect marks for the spelling test. He has to study hard to get the perfect mark. So, if he is upset when he is studying, he pinches Mum and shouts.

(Case 9, reviewing session)

Although not all the autistic children in this study were reported to have aggressive behaviours, the characteristics of autism, as perceived by their siblings, undermined their sense of safety (e.g. Benderix & Sivberg, 2007). Compared to the preceding accounts from the children (see above), their parents (Cases 1, 6, 7 and 9) did not recognize their normally developing children's needs for protection. Parents often

minimize and disbelieve the frightening experiences that make their normally developing children feel unsafe at home:

- Interviewer:** What do you do if A2 hits A1?
- Mother & Father:** Well.....
- Interviewer:** It could be painful.
- Mother:** Then,
- Father:** He does not hit her.
- Mother:** A2 does not often do it to A1.
- Interviewer:** Sure?
- Father:** He pinches or hits people, but not at home
- Mother:** A2 does not hit children. But the adults who try to make him do, or not do, things - especially the teacher.... Of course, he hits friends, but then shouts 'why do you hit me?'
- Father:** Nevertheless, A2 is not aggressive.

(Case 1, A1's parents)

This interview suggests that the parents did not recognize the degree of aggression directed towards their normally developing children even though they acknowledged their autistic children's aggressive behaviours. As a consequence, the personal environment and safety of the normally developing children became a marginal concern for parents, leaving the children uncertain about their own safety in the family home. It may be for this reason that all nine siblings considered school or *hakwon* as the best place to recharge, and where they could escape from their autistic siblings.

### 8.3.5. Financial Resources

The six oldest children in this study referred explicitly to the financial hardships that arise from special and future expenditure for their autistic siblings. For example:

I currently worry about money, yes, I'm concerned about money too much. I don't have good clothes. So, I was in my school uniform when I met you [researcher]. Of course, I had no time to change clothes, but, honestly, I don't have pretty ones; a few pairs of jeans, but they do not fit now. I would like to buy



several pairs of jeans, a hat, bag, shoes and some good food.....however, our family is poor. Honestly, my Mum and Dad graduated from good universities. My Dad has a postgraduate degree. Ah...here, I cannot help saying about H2. So ...I always used to complain ...I wish to be rich, have a lot of money. I questioned why my Mum and Dad were poor, why they have poor jobs. Whenever I thought, I reached the conclusion that it was H2.

(Case 8, aged 13, video diary-11)

Yes, my brother spends a lot of money now. .... but I spend money for only *hakwon*. In order to enter school, my brother is spending lots of money for [special education] kindergarten and so on. .... If my brother was not ill [disabled], my family would be rich a bit.

(Case 7, aged 12, reviewing session)

In these extracts H1 and G1 indicate the effects of financial difficulties associated with additional needs of their autistic siblings and increased hardships of daily life. Even two children (E1 and J1)<sup>58</sup> from high income families also indicated that living with autism was related to financial hardship:

**Interviewer:** In your video diary, you said about your father's job. Would you tell me more?

**J1:** An attorney earns more money than a judge. So I want to be an attorney. Although Dad is a judge, he really doesn't have money. He has difficulty paying the bills.

**Interviewer:** Why?

**J1:** Because of my brother. So, I really want to earn big money.

(Case 9, reviewing session)

**Interviewer:** If some people were willing to offer you any help, what would you ask for?

**E1:** Anything?

**Interviewer:** Anything you want. Would you tell me the most important thing?

**E1:** Money

<sup>58</sup> E1's father is banker, and J1's father is judge.

- Interviewer:** Money? Why?
- E1:** [Money] could be power, which would be able to get everything.
- Interviewer:** So
- E1:** I would spend money on a cure for my brother.
- (Case 5, reviewing session)

All the parents in the study referred to the impact of financial difficulties arising from having an autistic child on the opportunities for their normally developing children. For example:

- Mother:** It was very hard. Now, we have not been offered many services for C2. When he was younger, we spent nearly all our income on him. For example, our family income was 1,000,000 won (£500); we spent 700,000 won (£350) on C2. He got [private] art therapy for disabled children in Seoul, had Korean traditional herbal medicine and had individual special education from a private teacher for about 6 or 7 years. We spent most of our money on C2, although we could not buy [preferred] food due to financial hardship. So I could not invest in the education of the oldest one [C3]. She should go to *hakwon* and get additional study from a private teacher, but she couldn't. She got piano lessons only.
- Interviewer:** How about C1?
- Mother:** C1 did not get anything either. I hope I will invest in C1 in the future. But C2 gets support from the welfare centre now. So compared to the past, I spend little on him. In the case of school, he has been supported fully from school. When he was young, I paid the tuition fees of the kindergarten, and he got individual special education from a private teacher when he was in an elementary school. It was a really hard time. Now, currently, I spend lots of money on C3
- (Case 3, C1's mother)

H1 (Case 8)'s father said:

She had piano lessons at *hakwon*. Financially, we cannot properly support her.  
The tuition fee of *hakwon* is consistently increasing.

And G1 (Case 7)'s mother said:

**Mother:** If we were stable financially, we would give support to G1.  
Honestly, it would be better one-to-one tutoring than  
*gongbubang*. But I would have to pay two times more. Honestly  
I want to, but..

**Interviewer:** Do you feel.....?

**Mother:** ... I feel sorry for him. But we should spend money for G2  
now.

According to these parents' accounts, the available financial resources were easily diminished because of the additional needs of their autistic child, directly affecting the opportunities available to their normally developing children. Specifically, they felt sorry that they were not able to afford extra curricular education for their normally developing children.

The overall messages from this study about financial resources are that the additional costs of raising an autistic child lead to difficulties in the purchase of everyday commodities and reduced educational and social opportunities for siblings which in turn lead to poorer prospects for their future financial and social status.

### **8.3.6. Collective Support**

The children's video diaries and home movies made no reference to opportunities to talk about their experiences of living with an autistic sibling. As part of the reviewing sessions I explored this aspect of 'voicelessness' with all the children. Four revealed that they had some experience of attending a support group (discussed in section 8.3.6.1). I discussed with the other five children why they felt unable to discuss their experiences and feelings with others. Their responses indicated that their friends and parents would not understand them. They recognized that other children with autistic siblings may understand them, but they did not know any children in this position. In a

cultural context that equates disability in the family as a source of shame, it is unsurprising that collective support systems are unfamiliar. In the following two sections I present findings from the four families whose children did have experience of support groups and then the five families whose children had no such experience.

### **8.3.6.1. Children with Experience of Support Groups**

Only four children (Cases 3, 5, 7 and 9) in this study attended support groups. C1 and G1 had attended different support groups run by community welfare centres for disabled people some time earlier but no longer attended. E1 and J1 had attended ‘summer camps’ run by voluntary agencies. C1 explained:

When I was in Year 4, I joined in the support group run by the welfare centre, where my brother participated in the programme for disabled children. Siblings of disabled brothers were together and talked about younger or older siblings’ illness [disability]. I was a member of the group for 1 year.

(Case 3, reviewing session)

**Interviewer:** Have you ever joined in sibling support groups or siblings summer camp?

**E1:** Yes, I joined summer camp ..... It was fun .....  
My family, except Dad, joined together.

(Case 5, reviewing session)

All four children indicated that the benefits of their support group lay in helping them to be generally informed about disability and about other families’ experiences of living with disability, but it does not indicate that they had not got specific information about autism (see section 8.3.2.). Support groups also provided the opportunity to meet with other children who have disabled brothers or sisters and to share their own experiences of disability. For example:

**Interviewer:** Have you ever met other children or families of a child with autism?

- G1:** There, there in the community welfare centre where brothers and sisters discussed together.
- Interviewer:** Was it helpful?
- G1:** A little.
- Interviewer:** Would you tell me more?
- G1:** Watching videos and talking together.....
- Interviewer:** so
- G1:** When we were watching a video that was shown about autistic children.
- Interviewer:** Video? ..... were they very similar to G2?
- G1:** Yes. Whenever I watched the video, I found out about children who were similar to G2. They are really the same as G2.
- Interviewer:** Did you get help from the sibling support group?
- G1:** Yes, I could understand my mother, father and G2.

(Case 7, reviewing session)

- Interviewer:** Do you think it [support group] was helpful?
- C1:** It might be.
- Interviewer:** Might be, was it fun?
- C1:** Yes.
- Interviewer:** What kind of things did you like ?
- C1:** Sometimes, we played at play-gym on the top of the building, or we surfed the internet to look for information about our older or younger siblings' disabilities. Over time, I learnt about disabilities.

(Case 3, reviewing session)

However, the children were not always entirely happy with support groups. First, they were not comfortable with the mixed composition of the groups in terms of age and gender that sometimes made communication and participation awkward. G1 describes below the various ages of children in her group:

- Interviewer:** Have you made new friends?
- G1:** No. I was the second eldest child. The eldest sister is in Year 1 in middle school, and the youngest is in Year 3 or 4 in elementary school.

- Interviewer:** Did you work together with them?  
**G1:** With them? Not really.  
**Interviewer:** Why?  
**G1:** Because they were younger than me.

(Case 7, reviewing session)

G1's mother also commented that the ages (as well as gender) of group members are too disparate to be joined together in one support group:

Many people said 'we should use a sibling support programme' and I heard about the support programme in the welfare centre. When I applied, I asked 'G1, do you want to go to the group?' He said 'yes'. So he joined in the group without any specific intentions. But actually, G1 did not want to go there. I asked 'do you want go?' So he answered, 'well, how about you, Mum?' So I answered 'why don't you try it? But the other members of the group were younger, Years 1 and, 2. Only G1 was in Year 5. There was a girl who was in Year 6, but she did not often attend the group. He did not fancy being in the group because there were no children of his age.

(Case 7, G1's mother).

So, even when children joined support groups, their discomfort about differences in age and gender discouraged them from continuing to attend.

Difficulties also arose when children attended a group together with their autistic brother or sister, decreasing enjoyment of and participation in the group. J1's mother mentioned this problem:

- Mother:** In the summer vacation, a sibling summer camp was run by the day care centre. I suggested to J1 that he join in the camp as a volunteer, since all of the siblings [of disabled children] within the group were elementary school age, but J1 was in middle school. I supposed that he might not fancy playing with them, so I suggested that he go as a volunteer. At the time, his friend also joined in the camp. After he came back from the camp, I saw his diary; he wrote that he felt hardships, but it was a good

time because his teachers encouraged him. Then, he said 'Mum, J2 might be really the hardest child'. ..... In the church, there was a monthly social adaptation programme for disabled children. J1 joined in the programme several times. But then he did not want to go anymore.

**Interviewer:** Why?

**Mother:** Because he said that it was too hard and no fun. There was no friend who was the same age as him, and he just looked after his brother. Although he had no responsibility for looking after his brother, he was concerned about him. So he did not go anymore.

(Case 9, J1's mother)

J1's mother's comments show that attending the support group with an autistic brother or sister may increase the perceived care-burden of siblings. And, as a result, they may not be able to enjoy a sense of freedom at the group.

A third problem with support groups was that, although parents expected that the support group may be enough to influence siblings' daily lives, they showed no differences after participating in the support group:

I deliberately sent him to siblings support group in N community welfare centre. But he did not change.

(Case 3, C1's mother)

**Interviewer:** Have you found any difference after attending the sibling support group?

**Mother:** I haven't noticed anything different ..... other mothers suggested the sibling support group. So I just registered G1, although I did not know about it. Indeed, G1 was not willing to go. But I forced to him.

(Case 7, G1's mother)

These words indicate the deeply-rooted sense of parental authority and children's unquestioned obedience in Korean culture; factors that are likely to discourage children from expressing their own views and being involved in decision-making processes.

In summary, sibling support groups appeared to offer a valuable source of support, providing general knowledge about autism, various activities and opportunities to share siblings' own experiences; and may result in greater understanding and empathy for both parents and autistic siblings. However, the effectiveness of support groups was limited by the make-up of the group (e.g. age, gender and mixing children with their autistic siblings). And the perceived effectiveness of support groups was also limited as a result of unreasonably high expectations on the part of parents.

#### *8.3.6.2. Five Children's Experiences*

The other five children in this study had no experience of attending a support group. Indeed, neither they nor their parents knew what a support group involved. Even A1, due to attend summer camp, did not know what to expect.

**Interviewer:** Have you ever join in a sibling support group or day camp?

**A1:** No

**Interviewer:** Never?

**A1:** No, never

**Interviewer:** Do you know about sibling support groups?

**A1:** I don't know.

(Case 1, reviewing session)

**Interviewer:** Do you know about sibling support groups?

**Mother:** No. I just saw the title in a leaflet (A1's mother)

Although these five children and their parents did not know about support groups, they all expressed a need for support. The following example illustrates a desire for emotional support:



It would be better to talk with Mum and Dad, but I'm concerned [that] Mum and Dad [will worry] if I tell them my story. Although I often said I can endure whatever H2 has done, Mum and Dad do not know about my hardships. So it would be better talk with friends, but they do not understand my story. If they understand, I can tell them. That's a real help. If I make a friend who has a disabled sibling, I can talk and share common experiences. I can talk about my concerns to my friend, and then my worry will be gone. It will be good, fresh and fantastic. .... I would like to have friends who have an autistic sibling, and would be able to understand everything about me

(Case 8, reviewing session)

Here, H1 shows that she would like to be given the opportunity to express her concerns, and also to be listened to. Further, she wants to communicate these concerns to other siblings who are in a similar situation. But despite articulating a desire for support, the children had no clear expectations of what a sibling support group might offer. For example:

**Interviewer:** Are you going to join in sibling summer camp this summer?

**A1:** Well, it's the first time

**Interviewer:** Do you expect anything?

**A1:** Not at all. Just a short break at the island.

(Case 1, reviewing session)

As part of a reviewing session, H1 referred to her feelings that no one understood her situation because of the uniqueness of her situation:

**Interviewer:** Have you ever joined in a sibling support group?

**H1:** I would not like to go to that sort of siblings support group or camp.

**Interviewer:** Why?

**H1:** *Jjokpallyeo* [it is embarrassing] ..... [Support groups are] definitely not helpful to me. Other people's lives are no-one else's business. It will only be the same people who have a child with autism. It will not really be helpful.

(Case 8, reviewing session)

H1's words indicate that, although support groups may offer the opportunity to share common understandings and experiences with other siblings, she did feel they had the capacity to recognize the uniqueness of an individual's circumstances related to the severity of the autism and to each family's circumstances.

The parents of these five children were conscious of their children's need for support. But they were also aware of barriers that may prevent them from taking part in any form of group support:

- Mother:** To be honest, it [support groups] is very important if D1 needs support. Some time ago mothers also discussed running a sibling support programme.
- Interviewer:** Is there much support for siblings, for example, at community centres?
- Mother:** No, not really any.
- Interviewer:** How about community centre 'N'?
- Mother:** Well, it is very difficult to register there.
- Interviewer:** Is it only for registered children?
- Mother:** Yes, and there is no space in the group.

(Case 4, D1's mother)

Accessing sibling support groups is difficult for a number of reasons. To register for a sibling support group requires that the disabled child must be registered at the same community centre and, moreover, numbers in each group are limited.

The five children who had no experience of support groups did express a desire for support but did not necessarily feel this would be best delivered via a sibling support group. And, as parents pointed out, access to support groups was extremely limited.

## 8.4. Summary

The findings in this chapter indicate some of the vulnerabilities and unmet needs of the siblings of autistic children. Central to their vulnerability is their 'voicelessness'

reinforced by cultural expectations that as 'good' siblings they will be willing to take second place to their disabled siblings. Other vulnerability-related themes emerging from the data included parental inattention, poor information, impact on school work, lack of safe space and financial resources. A final consideration relating to children's vulnerability was the availability and role of social support mechanisms. Here I found limited experience of, and mixed views about, the provision and use of sibling support groups.

In the following chapter I draw together the material from chapters 5, 6, 7 and 8 to address the research questions and to evaluate the findings in the light of existing evidence and argument in the literature.

## **Chapter Nine**

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## **Discussion**

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## 9.1. Introduction

This chapter discusses the study findings in the context of previous studies and existing theories that have informed understanding of the lives of siblings of disabled children, drawing out key issues of debate and identifying theoretical developments. Addressing each of the research questions posed in chapter 2, I start by discussing the children's own meanings of 'being' the sibling of an autistic child (section 9.2) and argue that existing literature has not offered an adequate portrayal nor understanding of this experience within Confucian familist cultures. I go on to discuss how autistic children are perceived by their siblings (section 9.3), arguing that social-psychological perspectives on the consequences of 'having autistic siblings' provide only narrow and partial understandings of children's own experiences of everyday life. In contrast to widely adopted social-psychological and young carers' models of the 'family life of siblings of disabled children', section 9.4 discusses the social constructions created by the children themselves to reframe their experiences to achieve 'harmonious' family life. In section 9.5 I discuss the children's lived experiences in wider community and social settings that stand in sharp contrast to their 'ordinary' experiences of family life before moving on, in section 9.6, to address the complex relationship between children's resilience and threats to their wellbeing (referred to in chapter 8 as vulnerabilities). I argue that recognition and understanding of the children's unusual responsibilities, as a potential threat to their well being (despite the development of resilience) is a necessary precondition for effective policy and practice interventions.

## 9.2. Being a Sibling of an Autistic Child in a World of Confucian Familism

'Being a sibling' (Dunn, 2000; 2004) constitutes a very important aspect of any child's identity that goes beyond biology and socialization. 'Being a sibling' of a disabled child is a complex, paradoxical and ever-changing experience (Baumann *et al.*, 2005), and the meaning of 'being a sibling' in my study involves filial obligation throughout

the life-span for the benefit of the autistic sibling's well-being and to maintain family honour.

The demands of sacrifice on siblings and (more frequently) parents reported in literature relate directly to greater emotional or behavioural distress (Meyer & Vadasy, 1994; Horwitz, *et al.*, 1992). However, the findings from the sample in my study show that the demands involved in sacrifice, while eliciting some expressions of 'unfairness' and high levels of responsibility, also elicited a sense of pride and satisfaction. The sadness, hopelessness or depression noted in some Western studies were noticeably absent from the children's accounts in my study.

My findings suggest that the sacrifice of siblings is an integral aspect of normative cultural expectations. This contrasts with evidence and argument from Western literature<sup>59</sup>, that points to sacrifice: i) only in 'extreme situations' (Suzuki & Greenfield, 2002), ii) characterized by altruistic behaviour and iii) based on values of individualism and egalitarian relationships (e.g. Van Lange *et al.*, 1997; McGraw & Walker, 2007). For example, a study of Australian siblings of brain injured children (Bursnell, 2003:146-147) describes 'sacrifice' (of, for example, expression of emotion and position within the family) as an adjustment strategy by the individual child to respond to the 'vulnerability of life' and to restore equilibrium. Concurring with other Eastern Literature (e.g. Chee & Levkoff, 2001; Youn *et al.*, 1999), I argue that the sacrifice made by the nine non-disabled siblings of autistic children in this study is part of the fulfilment of normative expectations including filial obligation and filial responsibility. However, caution must be exercised in generalizing this argument to all Korean siblings of disabled children.

As with other studies that address family obligations in Confucian cultures (e.g. Fuligni *et al.*, 1999), my study confirms the high value placed on sacrifice by children, supporting the general assertion that Koreans have a strong sense of duty to their

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<sup>59</sup> The majority of published studies on siblings of disabled children emanate from Europe, Australia and North America and are characterised by quantitative approaches, examining predetermined hypotheses and measurement of emotional and psychological well-being (see chapter 2). With no available evidence based on visual ethnographies of the siblings of autistic children in Western cultures, it is important to acknowledge that the findings of this study must be interpreted not only in terms of cultural frameworks but also in terms of methodological approach.

families (Lee, K.K. 1998). Indeed the continuing and long-term needs of the autistic siblings elicited a very strong sense of filial obligation among the children in the study. My findings illustrate the ways in which siblings adopt their roles and affirm their position in the family, within dominant cultural codes related to gender and birth order: As with a number of Western studies that demonstrate older siblings taking higher levels of responsibility (e.g Van Riper, 2000; Rossiter & Sharpe, 2001; Rampton *et al.*, 2007), older brothers in my study were most readily willing to make sacrifices for their autistic siblings, though this was likely to be in the form of ‘supervising’ or accompanying (and financial support was strongly anticipated in future adulthood). This contrasted with sisters’ sacrifice characterized by domestic help or practical care (see Chung, E.S., 1993). In this context, the self identity of: i) brothers who are younger than their autistic sibling, and ii) sisters of any age, may be ‘spoiled’ (Goffman, 1963) in as much as their own experience differs from the expectations of wider society. Specifically, within the Confucian familist context, the sacrifice expected of adult sisters may mean that they face dual caring obligations to i) their autistic siblings and to ii) their own family including husband, children and parents-in-law. Consistent with McGraw & Walker’s (2007) American study of the sisters of disabled children, that found ‘good sisters’ self defined as ‘actively caring sisters’, the five non-disabled sisters in this study also expected to be actively supportive of their autistic siblings during childhood, adulthood and into their own marriages. This extension of support stretches beyond normative cultural expectations that see married women turn their attention to the well being of their husbands’ families.

The care responsibilities assumed by the children in my study were similar to those reported in the Western literature, which suggest that being a sibling of a disabled child is a ‘big responsibility’ (Baumann *et al.*, 2005:55; Damiani, 1999; Rodger & Tooth, 2004). Not surprisingly, the literature has emphasized the negative burden of the additional or exceptional responsibility, and argued that additional responsibilities for disabled siblings leads to: i) anxiety (Earley *et al.*, 2007), ii) sadness (Benderix & Sivberg, 2007), iii) worries about the future (Bägenholm & Gillberg, 1991; Meyer & Vadasy, 1994) and iv) feeling over-burdened (Opperman & Alant, 2003). Other research has found that siblings may be expected to mature more quickly (Glasberg, 2000) or to protect other family members from additional stress (Bursnall, 2003).

While my study of Korean siblings also shows restricted opportunities, conscious consideration of the future, and the protection of other family members, it is important to recognize that reluctance to make such sacrifices for their autistic siblings would be seen as a direct challenge to normative expectations. Although traditional Korean cultural values are being influenced by values associated with globalization and rapidly changing social conditions family structures (Choi, S.J., 2004; Kim & Min 2006), the non-disabled siblings in this study were still strongly influenced by the cultural value of filial obligation. They acknowledged and accepted that significant on-going sacrifice would be involved in meeting their filial obligations to their autistic siblings. This situation reflects official Korean data showing 99.2% of disabled people of any age being looked after predominantly by their own family members, and 89.3% of disabled people living with their families in 2005 (see Tables 9-1, 9-2). The same Tables show 100% of developmentally disordered (including autistic) people living with, and requiring on-going assistance from, family members. My study reflects this picture and, taken together with the national survey (Byun *et al.*, 2006a), suggests that the strong ideology of filial obligation continues to influence the pattern of care for disabled or chronically ill people by their families (Kim & Lee, 2003; Shin, J.Y., 2002; Kim & Theis, 2000; Cho & Kim, 2006).

In contrast to Western literature that focuses on practical care of disabled children by their siblings during childhood (e.g. Burker & Montgomery, 2003; Baumann *et al.*, 2005), my findings show that the responsibilities of siblings are expected to extend into adult life. Patterns of sacrifice grounded in filial obligation involve continuing acceptance of practical, financial and social responsibility for an autistic sibling as well as for their partners, children, and parents/parents in law. While a sense of continuing obligation to disabled siblings in adulthood is noted in the British literature (Hirst, 2001; Becker & Becker, 2008) the numbers of adult sibling carers identified by the General Household Survey are considered too small for statistical analysis (Hirst, 2001: 352). And newly emerging evidence about young adult carers aged 16-24 (Becker & Becker, 2008) does not differentiate the experiences of caring for parents and caring for siblings. What Becker & Becker (2008) do note is that 'the amount of caring could decrease as their brother or sister matured and they were able to do more for themselves' (p3). A



clear contrast between the experience of Korean siblings of disabled children and those in Western countries is linked to the role of the state in supporting disabled people and their families. As outlined in chapter 2, Korean social policy continues to be underpinned by cultural values that place central importance on family responsibility and family duty (Jang *et al.*, 2006). And the notion of 'sacrifice' in Confucian culture is considered the 'utmost expression' of reverence and humanity (Yao, 2000:193). Within the family, willingness to sacrifice is closely bound up with 'filial piety' a core characteristic of Korean culture (Sung, K.T. 1998b) and Tamai & Lee's comparative study of Japanese and Korean students (2002:39) found that Korean students regarded part of the 'self' as 'a presence for the welfare of others'. I do not argue that this sense of 'sacrifice' is never present in Western cultures, but there is no evidence of the **culturally** imposed obligation on the siblings of disabled children that is clearly reflected in the accounts of all nine siblings in my study.

Although Confucian familism has a weaker grip on contemporary family life in Korea (Yang, O.K., 2001) as shifts to Western values have placed greater emphasis on individual freedom (Na & Duckitt, 2003), traditional cultural values remain strong in some areas. My findings show that the lives of siblings of autistic children are still dominated by values of Confucian familism. However, although the children in my study had clearly internalized these values, and identified themselves as making sacrifices for their autistic siblings, they did not interpret or experience their sacrifice as wholly negative. They took pride in their abilities as 'good siblings' and as 'good children' in fulfilling their filial obligations to their parents. These findings contrast with other East Asian studies (e.g. Wang & Martinson, 1996; Ishizaki *et al.*, 2005) in which traditional values are reflected as negative aspects of siblings' experiences.

**Table 9-1 Disabled People (all ages) who live with Caregivers in The Same Household**

Classifications	Physical	Cerebral Palsy	Blind	Deaf	Verbal Language	Mental retarded	Developmental disorder (inc. autism)	Mental disorder	Kidney	Cardiac	Respiratory	Liver	Face	Internal organ	Epilepsy	Total
Yes	88.3	89.3	88.3	86.8	88.3	95.8	100.0	80.0	92.8	90.2	85.1	100.0	100.0	100.0	90.4	89.3
No	11.7	10.7	11.7	13.2	11.7	4.2	-	20.0	7.2	9.8	14.9	-	-	-	9.6	10.7
total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
(N)	(830)	(566)	(168)	(243)	(24)	(257)	(57)	(118)	(47)	(51)	(42)	(13)	(2)	(17)	(20)	(2,455)
National Estimated Number	322,141	218,423	65,273	93,596	9,364	98,219	22,465	45,070	17,837	19,483	16,236	4,970	786	6,542	7,496	947,901

**Table 9-2 Disabled People (all ages) Requiring On-going Assistance from Family Members Living in The Same Household**

Classifications	Physical	Cerebral Palsy	Blind	Deaf	Verbal Language	Mental retarded	Developmental disorder (inc. autism)	Mental disorder	Kidney	Cardiac	Respiratory	Liver	Face	Internal organ	Epilepsy	Total
Yes	99.0	99.2	100.0	100.0	100.0	98.8	100.0	98.9	97.7	98.2	100.0	100.0	100.0	100.0	100.0	99.2
No	1.0	0.8	-	-	-	1.2	-	1.1	2.3	1.8	-	-	-	-	-	0.8
total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
(N)	(732)	(503)	(149)	(209)	(21)	(244)	(57)	(93)	(44)	(46)	(36)	(13)	(2)	(17)	(18)	(2,184)
National Estimated Number	284,308	194,290	57,631	80,769	8,266	93,337	22,465	36,065	16,553	17,583	13,820	4,970	786	6,542	6,776	844,161

Cited: Byun *et al.* (2006a) 2005 National Survey on people with disabilities. p.195.

### 9.3. Children's Perceptions of their Autistic Siblings

This section presents the ways in which the non disabled children perceived their autistic siblings and the relationships between them. There is a widespread image of siblings being subject to a range of risks, because of the huge impact of their siblings' disability (Burke, 2004; Dykens, 2005). Contrary to previous research and theory grounded in social psychological perspectives, the children in my sample did not perceive their autistic siblings or their sibling relationships through a lens of 'disability'. This finding is consistent with the work of Connors & Stalker (2003; 2004) Davis & Salkin (2005) and McGraw & Walker, (2007) in which children's own accounts indicate that they perceive their disabled siblings, and their relationships with them, as very ordinary. Connors & Stalker (2003, 2004) found a picture of typical sibling relationships, with feelings of fondness and loyalty underlying routine bickering, irritation and rivalry. My study suggests that siblings do not inevitably have emotional and behavioural difficulties due to having an autistic sibling. Rather, they viewed their autistic siblings primarily as 'brother or sister' rather than 'autistic', and described their sibling relationships in terms that also describe typical sibling relationships characterized by 'ups and downs' (see chapter 6).

It is important to note that the perceptions of the children in my sample differed in complex ways linked to age and birth order:

- i) four children aged 12 and 13 (Cases 5, 7, 8, 9), who were older than their autistic siblings, described changes over time in the ways in which they viewed their autistic siblings. They had each gained more understanding of their sibling's condition and developed skills for coping with the more challenging aspects of autism;
- ii) all the children who were older than their autistic siblings (Cases 4, 5, 7, 8, 9) presented a more positive approach in describing their perception of their autistic siblings and showed a strong sense of obligation as the older sibling;
- iii) the three youngest children aged 7 and 8 (Cases 2, 4, 6) each had less understanding of their sibling's condition, and had not yet developed *Jeong* (see chapter 6). However, Cases 2 and 6, who were younger than their autistic siblings expressed more negative feelings than Case 4. Case 2, for

example, referred to ‘hiding his autistic brother’ and Case 6 expressed strong feelings of ‘unfairness’ (what she perceived to be preferential parental treatment of her older autistic sibling that was contrary to normative cultural expectations of younger siblings). In contrast, Case 4, who was older than her autistic brother, expressed pride in her ability to play with and care for her younger brother.

- iv) the four children who were younger than their autistic siblings (Cases 1, 2, 3, 6) showed greater difficulty in coping with their autistic siblings and described their relationships in ways that were consistent with terms of ‘up and down’ (Connors & Stalker, 2003).
- v) Cases 1 and 3, aged 15 and 13, despite having reached adolescence, showed less development in understanding and coping skills than the adolescents who were older than their autistic siblings.

**Figure 9-1** Model of Relationships Between Autistic Children and Their Siblings

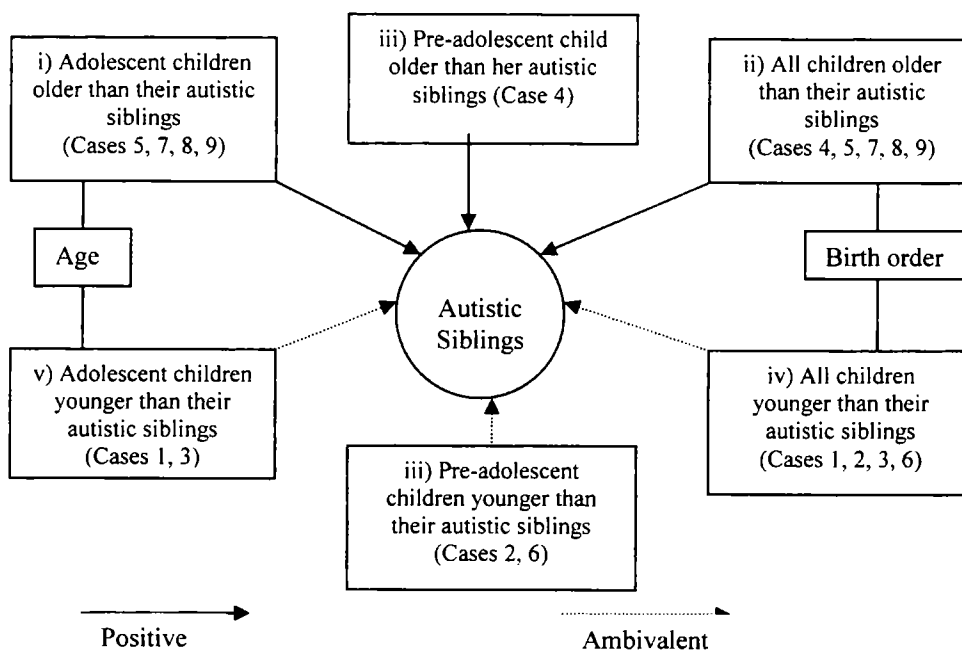


Figure 9-1 presents a model of the relationships between the children in my study and their autistic siblings showing birth order and age as important factors in determining

the nature of the relationships, in line with the normative expectations of sibling relationships in Korea.

This model, however, fails to capture the understanding of four children (Cases 3, 5, 8 and 9) who construed developmental changes in symptoms and characteristics of their siblings' autism as 'getting better', or signs of recovery. Such understanding coincides with Lobato's (1990) argument that most children describe their disabled siblings in terms of appearance rather than their impairment. Claims of 'getting better' or signs of recovery should not be understood as simple denial of impairment (see Hames, 1998; Shakespeare, 1999; Watson, 2002; Connors & Stalker, 2003, 2004). Rather, it seems that the children felt ambiguous about their autistic siblings' unexpected and unpredictable behaviours, and their views of their autistic siblings fluctuated in response to changes in their siblings' behaviours. This echoes the findings of Seo H.J.'s (1999) study of 46 Korean children with autistic siblings that found over a quarter of the children expressing fear of their autistic siblings. What is important in my study, however, is that autistic siblings were an integral part of the children's everyday lives and perceived primarily as 'brother' or 'sister' rather than as 'autistic'.

With regard to sibling relationships, my findings illustrate that all children except Case 2 described their relationships with their autistic siblings in terms of 'sameness', and all children also described their relationships in terms of 'difference'. These results reflect findings about siblings reported elsewhere (Connors & Stalker, 2004; Davis & Salkin, 2006; McGraw & Walker, 2007). Shared activities on a daily basis and the development of effective communication between siblings help to create and maintain a sense of strong sibling relationships or 'sameness'. However this sense of 'sameness' did not prevent children from seeing themselves as intrinsically different from their disabled siblings. All the children in the sample were deeply aware of the deficits associated with their siblings' particular type, and severity, of autism, and constructed a clear sense of 'difference' that presented some difficulties in developing and maintaining satisfying sibling relationships.

While many earlier studies have emphasized the complex and inconsistent effects of disability and autism on sibling relationships (e.g., Mates, 1990; Rodrigue *et al.*, 1993;

Kaminsky & Dewey, 2002), my findings show that strong sibling relationships are perceived in terms of wider, culturally prescribed, interpersonal relationships such as *Jeong* and *Woori*. Six children (Cases 1, 3, 5, 7, 8 and 9) placed normative (*Jeong*), rather than pathological or dysfunctional value on their autistic siblings reflecting Davis & Salkin's (2005) argument, that the dynamic sibling relationship is based on 'being' siblings rather than on a consciousness of disability.

In contrast with many Western studies that focus on a simple binary of positive and negative aspects of sibling relationships (Mates, 1990; Bågenholm & Gillberg, 1991; Gold, 1993; Rodrigue *et al.*, 1993; Kaminsky & Dewey, 2002; Pilowsky *et al.*, 2004), my findings suggest that sibling relationships are experienced in terms of strength (*Jeong* - see chapter 6) rather than positive/negative. The only other example of an empirical study that focuses on *Jeong* based relationships (Cho, Y.T., 2002) describes a sample of children with learning difficulties as *Jeong*-full, indicating the formation of strong relationships with others. Although my study did not collect evidence of *Jeong* among the autistic children, their siblings developed a special mixed type of *Jeong* with them, combining a complex mixture of positive *Goun-Jeong* and negative *Miun-Jeong* aspects. Based on *Jeong*, the children described very strong sibling relationships, incorporating physical and emotional manifestations of collectivist concepts such as '*Woori*' (togetherness). Although notions of individualistic familism (see chapter 6) have spread rapidly among Korean young people (Chang, K.S., 2003:598), the sibling relationships in my study were still clearly characterized by traditional cultural norms of Confucian familism.

Strong sibling bonds are associated with the fundamental value of being a 'good sibling' in Korea. Children grow up together and think of themselves as a part of 'ours' by blood-tie; relationships which are not voluntary but given by nature (Phuong-Mai *et al.*, 2005:405). In my sample, all children expressed strong relationships with their autistic siblings emotionally and geographically based on *Woori*. But the large majority of studies present sibling relationships with autistic children with less healthy levels of pro-social behaviour, intimacy, and nurture by siblings because of the various social deficits associated with autism (e.g. Knott *et al.*, 1995; Kaminsky & Dewey 2001). My study also questions findings that indicate a direct relationship between increasing

severity of an individual's impairment and poorer sibling adjustment (e.g. Gold, 1993; Pilowsky *et al.*, 2004). For example, G1 (Case 7, older brother) and A1 (Case 1, younger sister) had developed very strong relationships (*Jeong* and *Woori*) with their siblings despite their persistent and particular challenging behaviour.

Previous European American literature has generally adopted a psychological approach for studying relationships between disabled children and their siblings and they generally report negative effects on siblings with only a small number of studies reporting any positive effects. My study has focussed less on the positive and negative effects of autism since I found that this is not how the siblings of autistic children experience their worlds. Rather, they experience their autistic siblings as 'my brother' or 'my sister', not as 'autistic'. I argue, therefore, that based on strong cultural values of siblinghood, *Jeong*-based and *Woori*-based relationships foster normative, albeit unique, experiences between siblings.

#### 9.4. Harmonious Family Daily Life

Autism does not exist in a vacuum, but affects the whole of family life. Disability is often assumed to be a personal and familial tragedy (Oliver, 1990). An extract from Davis & Salkin's (2005)'s study of the siblings of disabled children illustrates this point:

What seems clear to me is that any disability Kathy had was a 'family disability', experienced in relationships between our family members (p.210).

The life of a family with a disabled child is commonly associated with stress, conflict, less full participation in community, financial hardship, maternal depression, marital distress, and loss of childhood, with routines revolving around a disability or chronic illness (e.g. Hand *et al.*, 1994; Seligman & Darling 1997; Nixon & Cummings, 1999; Dowling & Dolan, 2001; Mandlco *et al.*, 2003; Pit-ten Cate & Loots, 2000; Rivers & Stoneman, 2003; Verté *et al.*, 2003; Dykens, 2005). Other studies (Chung & Lee, 2001; Oh, S.A., 2002; McGraw & Walker, 2007; Grinker, 2007), identify significant risk

factors for families with low socioeconomic circumstances, smaller families (in which siblings have to assume a greater share of the caregiving), and for sisters, who also often have greater caregiving responsibilities (Sanders, 2004:128-129; Opperman & Alant, 2003; Miller, 2001). The popular image is of family life being overwhelmingly more stressful for families with autistic children than for families with children suffering from other disabilities or chronic illnesses (e.g. Sanders & Morgan, 1997; Sivberg, 2002; Lecavalier *et al.*, 2006; Blacher & McIntyre, 2006). This image is further reinforced by the image of the 'disabled family', which has been depicted as improper or incomplete in Korea (Kwon, M.O., 2000). However, the children in the study sample were able and willing to accept the personal implications and effects on daily family life of living with an autistic sibling, in an attempt to seek and achieve harmonious family life.

I do not claim that 'harmonious family' equates to being 'challenge free'. Indeed my study illustrates that the ambiguity, uncertainty and unpredictability of autism can have damaging consequences for siblings' daily lives within the family, such as different parental treatment, taking second place, and disruptive family life. The children were aware of daily routines in families without disabled children and saw their own everyday lives as being 'not like other families'. However, my findings illustrate that siblings revise and reconstruct the consequences of living with an autistic child through a continual process of 'seeking and achieving balance' in the same way as unexpected changes due to disability or chronic illness require new adjustments in everyday life (see e.g. Taylor *et al.*, 2001; Sharpe & Rossiter, 2002; Hastings, 2003a; Guite *et al.*, 2004; Bursnall, 2003; Burke, 2004; Davis & Salkin 2005; Wilkins & Woodgate, 2007).

The findings of my study are likely to be strongly influenced by the ideology of 'harmonious family life', one of the basic values of Confucian familism in Korea (Callahan, 1999:344). Confucian familism stresses harmonious hierarchical relationships among individuals and puts great importance on harmony, cooperation, consensus and social solidarity among members of an organization rather than on an individual's preferences (Lee, J.H., 2003; Lynch & Hanson, 2004). Family harmony is of central importance within Confucian cultures with greater emphasis on collectivist than individualist values. Confucian cultural values are commonly contrasted with Western cultural values on this basis (Hofstede, 1991; Triandis, 1995) with the latter



placing more, though not exclusive, emphasis on individualism, self-reliance, autonomy of thought and action (Leininger, 2002:290).

The normative beliefs that form Korean socio-cultural expectations of the family consider that the most important elements for 'happy' families are health, trust, understanding, acceptance and respect, together with feeling comfortable and emotionally supported (Park, M.J., 2006). Based on the cultural ideology of family as the best form of social security, siblings in my study sought to create these elements in order to achieve a 'harmonious family life' both within the family, and to present to the outside world. As a result, they accept parental inattention, and refocus priorities by accepting second place. They adapt to certain degrees of loss of family life in order to establish a sense of coherence and control within the family (see King *et al.*, 2006). And they describe largely unrestricted and inclusive family daily life (e.g. shopping and outings to restaurants with their autistic siblings). This contrasts with the findings of Western studies in which families experience significant restrictions associated with the presence of disabled children (Gamble & McHale, 1989; Roeyers & Mycke, 1995; Ross & Cuskelly, 2006). Gray's Australian (1997) study argues that the construction of ordinary family life for families with autistic children is linked to factors such as the ability of family members to socialize, the emotional quality of the interactions among family members, and the rituals and routines that comprise their perceptions of what ordinary families do. Based on the findings of my study, I argue that the achievement of harmonious daily life within the family involves enabling siblings to function effectively within the family, maintaining the integrity of the family and the family equilibrium.

Another way that siblings in my study contributed to the achievement of harmonious family life was by contributing to caregiving activities, necessary to enable and protect their autistic siblings. While children within Western cultures may also contribute to the care of vulnerable members of the immediate family (e.g. Winton, 2003), importance is placed on the development of their own self-reliance, self-competence and independence (Kağıtçibasi, 1997). By contrast, the socialization of Korean children focuses primarily on the maintenance of family harmony (e.g. Lee, E.O., *et al.*, 1999; Farver *et al.*, 2000). Within an ideology that values harmony in family life, 'sacrifice'

plays a strong role in the pursuit of family happiness and cohesion (MOGEF, 2006). This has the effect of ‘normalizing’ parental expectations of siblings and the acceptance by siblings of these expectations.

A point repeated in the literature (Burke & Montgomery, 2000, 2004; Robson, 2000; 2004; Dew *et al.*, 2004; Robson *et al.*, 2006), is that children are recognized as an important source of complementary support for main carers (Beresford, 1994; Katbamna *et al.*, 2004). In contrast, the caregiving activities by the nine siblings in this study, based primarily on filial obligation, remain largely unacknowledged in wider society.

It would be a mistake to place exclusive emphasis on cultural specificity as the basis of Korean children’s experiences of living with and caring for disabled siblings. In studies of young caregivers in Lesotho, Tanzania and Zimbabwe, Robson *et al.* (2006) articulate i) strong bonds of intimacy, reciprocity and responsibility assumed by children as caregivers in the context of the HIV/AIDS pandemic, and ii) children’s perceptions of the benefits and privilege associated with the responsibility of caring for close family members. And in studies conducted in Western cultural contexts (e.g. Aldridge & Becker, 2003; Becker & Becker, 2008), caring relationships between children and their vulnerable family member are described as being founded on reciprocity and interdependence. My argument is that the factors that motivated and sustained the sample of Korean children in their caregiving roles, are bound up in the strong ties of love and affection (*Jeong*) that form the basis of reciprocal filial piety (Yeh, 2003). But they are also firmly underpinned and reinforced by authoritarian filial piety (Yeh, 2003) that characterizes family relations and attributes honour and shame to those who meet, or fail to meet, the expectations associated with filial piety. The persistent strength of Confucian familist values in Korean society has prevented the creation of spaces for the public recognition of children’s roles as caregivers, the recognition of ‘children’s rights’ in individual terms, and the development of policy and practice to support child caregivers.

In a Korean study of caregiving work in the families of disabled children conducted by Jang *et al.* (2006), the role of siblings was conspicuous by its absence, reflecting a research design that failed to acknowledge the possibility of children’s roles in

caregiving. In line with my study, I suggest that the normative expectations relating to caregiving within families, as a part of the fulfilment of filial obligation, leads to the denial of 'shameful family matters' and failure to acknowledge or articulate the role of siblings in caregiving activities and responsibilities. In the West, the caregiving contributions of siblings are more widely acknowledged through recognition as 'young carers', offering help considered additional to that which may be expected within families without a disabled children (Burke, 2004:67-68). I do not wish to overstate recognition of 'young carers' since the criteria for deciding young carer status remains ambiguous. The definition or nature of a sibling's role as 'carer' may be complex and depend upon a variety of factors, as suggested by evidence from other research (Becker *et al.*, 1998; Aldridge, 2007a; McClure, 2001; Eley, 2004; Becker, 2005, 2007).

In seeking to understand siblings' caregiving behaviour it is very difficult to distinguish between the values of sacrifice and obedience (both elements of filial obligation) in a Confucian familist cultural context. This leads me to argue that there is a normative expectation of family caregiving in Confucian familist culture that has not been clearly articulated in the terms of care as work within the home. Caregiving within the family is still assumed to be limitless and a perpetual responsibility rather than unpaid work or labour (see Becker 2007; Aldridge, 2007a). There is no definitive statement or support service recognizing family care working in Korea. Nevertheless, I suggest that over-reliance on existing cultural norms governing caring within the family may prevent the identification of children who carry responsibilities that have been perceived elsewhere as parental responsibilities (see Shah & Hatton, 1999; Jones *et al.*, 2002; Robson *et al.*, 2006).

This discussion of siblings' efforts to create a harmonious family life demonstrates an interesting paradox in which: i) the value of 'harmonious family life' is a strong motivation to create 'ordinary' family life while ii) the very efforts that support the construction of harmonious, ordinary life, make the contributions of siblings 'invisible' to the outside world, and 'taken for granted' by family members who readily accept the cultural norms of filial obligation, filial piety and sacrifice. I argue a need to address this paradox, but also argue for an approach that avoids the use of the oversimplified term 'young carer' that may become an inappropriate label. Non-disabled children's

contributions to the care of their disabled siblings are found in evidence from research across nations (see chapter 2). In the UK context Burke (2004) argues that such siblings are considered as young carers in recognition of their additional and unusual caring activities for a disabled child. However, Olsen (2000) also writing in the UK context, argues that while many children undertake similar tasks in contributing significantly to housework or the care of their siblings, it is only the siblings of disabled children who are identified as young carers. In the Korean cultural context, I argue that to ascribe the siblings of disabled children as 'young carers' would be tantamount to devaluing the cultural norms that contribute to family harmony.

These findings and my interpretation of them, do not suggest that the siblings of autistic children are free of difficulties and problems in everyday life. However, the findings do demonstrate that all, and particularly the six older, siblings derived a strong sense of achievement and honour in being able to fulfil expectations associated with filial obligation and maintaining family harmony. This contrasts with the conclusions of studies carried out in Western contexts that are informed by different cultural values. For example, in the UK context Dodd (2004:43) argues that 'it is essential that siblings of disabled children are not obliged to take on roles beyond their age and ability'. But children's rights in Korean society retain a strong element of Confucian familism and are expressed as 'family integrity rights' (Yang, S.N., 2008). For example, filial obligation is the accepted way of maintaining family harmony (Sung, K.T., 1996). Viewed from Western perspectives of children's rights, the honourable acceptance of roles and responsibilities by the non-disabled siblings in this study might be regarded as the socially sanctioned oppression of children. However, concepts of rights and duty differ between Korean and Western cultures. For example, according to Hoppe-Graff & Kim's research (2004) involving German and Korean adolescents, the concepts of rights and duty in Korean adolescents were related to the *inner experiences* that derived from having particular rights connected with having particular duties such as obligation and responsibility. In contrast, for the overwhelming majority of the German adolescents in the study, duty meant simply that 'you have to do something' and rights were connected to legality or 'being allowed to do something'. Such differences are attributed to a pronounced diversity of cultural experience.

The argument, on the basis of my study, is that promoting the interests and well-being of non-disabled siblings of autistic children in Korea requires: a) the development of strategies to ensure that their voices are heard, while also b) respecting Korean Confucian cultural influences related to family privacy, parental authority and family harmony and c) acknowledging the unusual opportunities (Miller, 1996) experienced by non-disabled siblings who, in Western contexts, would be identified as ‘young carers’.

### **9.5. Reconstructing the Experience of Living with an Autistic Sibling in Wider Society**

The daily lives of the children in my sample within wider society have been strongly influenced by negative socio-cultural images of autism. Ideas of, and attitudes towards, disability are deeply embedded in communities and cultures (e.g. Shakespeare, 1994; Gilson & Depoy, 2000; Ali *et al.*, 2001; Rao, 2006). For example, Connors *et al.* (2004), writing about Pakistani and Bangladeshi families of disabled children in the UK, reported that while the parents felt a sharp sense of loss or tragedy linked to shame and stigma, their non disabled children expressed a sense of disappointment, articulating their compassion and empathy arising from the loss of opportunities for joint activities with their disabled siblings. These children were, of course, being brought up at the interface of two cultures with different attitudes to disability. All the children in my sample experienced high levels of public prejudice and disabling attitudes that created attitudinal and environmental barriers, preventing them from participating **fully** in wider society.

Based on the cultural model of disability (Snyder & Mitchell, 2006; Devlieger *et al.*, 2003), my study illustrates that the disabling stereotypical image of autism in Korea, based on cultural shame, has a negative impact on the daily lives of autistic children and their siblings in wider society. My findings echo Grinker’s (2007: 239) argument that ‘in Korea, autism confronts a different cultural framework’, and fits the profile of a condition that carries a high level of stigma (see Goffman, 1963; Kim, S.H. *et al.*, 2004).

My findings also confirmed that 'Koreans are less accepting of and less knowledgeable about disabled people' (Cho *et al.*, 2003:16). I argue that the social barriers and prejudicial cultural images of disability cannot easily be removed by simply adopting the social model of disability (Oliver, 1990; 1996; Marks, 1999; Swain *et al.*, 2004).

The strength of negative social attitudes to disability associated with traditional beliefs about the causes of impairment (see page 62) continues to create significant barriers to the effective use of the social model of disability to inform cultural change. Membership of the United Nations and conformity to international Human Rights conventions has obliged Korea to adopt a visible response to the social exclusion of disabled people through welfare legislation such as the Anti-Discrimination Act 2008. But the social model remains, for the time being, of limited utility in countering powerful socio-cultural values that characterise disabled people as '*Ijil*' or 'other'. As noted in chapter 3, Kim & Kang's (2003) study of young physically disabled Koreans show how the 'problem' continues to be perceived as being within the disabled person, not in the reactions of wider society. The children in my study experienced disability and disablement as a cultural phenomenon experienced through unfavourable attitudes towards them and their autistic siblings that made them feel that they, and their autistic siblings, were devalued, discounted, and discredited.

In line with previous literature, (Gilson & Depoy, 2000), my study also found that language used about autistic children often includes offensive terms. Words such as '*Aeja*' (young people's slang for disabled person) or '*Michin*' (mad/crazy) were identified in my study, and the use of offensive terms surrounding disability in Korea is discussed at greater length by Choi & Lam (2001) and Choi & Lee (2005). This powerful, negative, use of language perpetuates images of 'abnormality' and contributes to siblings' experiences of a 'secondary form of disability' (Burke 2004:44) in wider society. Consistent with previous studies (e.g. Gray, 1993) my findings showed that all the children's social lives were often affected by strong negative attitudes towards their autistic siblings, ranging from mockingly imitative behaviour to staring, in public. And like Beasley & Moore's (1996) study, my findings suggest that siblings face uncertainty between two worlds of 'ability' and 'disability' because they experience prejudice even though they themselves are not autistic. As Connors and Stalker (2004) have argued,

siblings 'have access to society's view of difference, which tends to be equated with 'abnormality', but also face the challenge of moving the boundaries of normality in order to include their sibling' (p. 227).

The childrens' social lives were also restricted as a result of public reactions, such as staring, to behavioural symptoms of autism that are perceived as 'strange' and 'different'. As a result, social inclusion is harder to achieve since this would require awareness and understanding of autism by Korean society. In this sense my findings echo those of Western studies which show that siblings of autistic /disabled children experience a restricted social life, socialization difficulties, loneliness and restricted peer relationships (e.g. Kendall, 1999; Eisenberg *et al.*, 1998; Bågenholm & Gillberg, 1991; Roeyers & Mycke, 1995).

Despite the difficulties and challenges faced by the children in my study, the findings illustrate that having an autistic brother or sister is not the catastrophic experience implied by Korean cultural norms that associate any form of disability with shame. Social prejudice and other barriers in wider Korean society did not prevent siblings from having a social life. None of the children in my sample were prevented from participating in social activities, daily routines or social circles which contrasts with other studies (e.g. Howlin, 1988; Bågenholm & Gillberg, 1991; Roeyers & Mycke, 1995; Connors & Stalker 2003; Lee & Kwon, 2002). One conclusion drawn from my study, therefore, is that living with an autistic sibling in urban Korea cannot usefully be conceptualized merely in terms of restrictions.

Autism is a largely invisible condition and the impairments associated with autism are neither easily recognized nor understood. My findings illustrate that the siblings of autistic children are in a position to directly influence the outcome of prejudicial reactions of others. All the children in my sample experienced provocative reactions from members of the public (Kwon, M.O., 2000; Connors & Stalkers, 2003; Burke & Montgomery, 2003) who have been socialized according to normative expectations of behaviour and who 'categorize' disability (including autism) as 'unexpected' and 'different'(Rao, 2006:161). These findings indicate that traditional cultural beliefs surrounding disability persist in contemporary Korea. Six of the nine children (Cases 3,

4, 5, 6, 8 and 9) in the study reframed their experiences of negative public reactions in which they risked losing *Chemyon* (losing face) in order to address the dissonance between socio-cultural realities of disablism and their daily reality of 'ordinariness'.

By using the Foucauldian approach of '*making the familiar strange or strange familiar*' (Foucault, 1988; 2002), my findings demonstrate how siblings reframed the strangeness associated with unpredictable autistic behaviours in public. For the children in my sample, having an autistic sibling was no more, no less, than a 'natural part of life'. By successfully reframing their negative experiences, the children achieved effective coping skills to deal with the dominant socio-cultural expectations of disability in general and autism in particular.

The findings of my study indicate that the siblings had different perceptions and understandings of autism. They were engaged in a continual process of understanding the balance of expected and unexpected behaviours of their autistic siblings, a process clearly rooted and reflected in the cultural model of disability. They saw their siblings' autism not only as 'disability', but also as 'ability'. All the children in my sample described their siblings' autism as 'illness'. And changes in symptoms led them to believe that autism could be cured (see section 9.3.). Their understandings of autism focused on their siblings' abilities such as communication, achievement in school and skills in the use of technology. The result of focussing on abilities enabled them to avoid long term negative constructions such as sins or evil deeds of ancestors (Erickson *et al.*, 1999) and to reconstruct the consequences of autism as being 'amenable to change' that can be negotiated to achieve inclusion in society. In contrast to Katbamna *et al.*, (2000) who state that South Asian carers take extra precautions to hide any conditions with invisible symptoms of disability, my findings illustrate that children value and take pride in the abilities of their autistic siblings. It is an important theoretical point that siblings' perceptions and understandings of autism and its social implications develop against the background of culturally embedded and powerful socio-cultural norms surrounding disability. These findings complement and go beyond those of Mir & Tovey, 2003: 470, who argue that '[Asian] parents [in Britain] are more likely to move away from the idea that disability is 'tragic' when they have information



that promotes a positive approach and when they are able to manage their circumstances without struggling.'

The theoretical argument of my study is that culture makes a strong contribution in the identity formation of siblings of autistic children and their relationships in daily family life as well as in wider society. If viewed through a lens of traditional Korean culture, living with an autistic sibling would be perceived as shameful. But siblings see their autistic siblings simply as brother or sister, and autism is integrated as a part of ordinary daily life despite experiencing stigmatized cultural attitudes from members of the public.

### **9.6. Valuing Children's Resilience and Respecting Children's Rights**

Despite the non-disabled children's own emphasis on 'sameness', 'ordinariness' of everyday experiences, and despite evidence of the development of resilience in the children in this study, it is evident that the children's experiences remain largely unacknowledged, and largely unknown outside the family sphere. In this sense the children remain unheard, and easily ignored by wider society.

It is therefore important to understand the nature of resilience in the Korean Confucian context. Ungar's (2008:220) work on resilience across cultures argues that resilience is not a condition of individuals alone, but also exists as a trait of a child's social and political setting, and the role of culture is very important in the promotion of resilience in children (e.g. Arrington & Willson, 2000; Cameron *et al.*, 2007; Ungar, 2008). As Wong (2004) has argued, resilience is conceptualised rather differently in Western and Confucian cultures. In the latter, individual resilience is perceived as the ability to conform to family and wider social expectations in the face of adversity in order to maintain family and social harmony (Tseng, 1973).

The ability of individuals to overcome adversity in Korean culture is embodied in the concept of '*han*'. But, unlike the concept of resilience that is associated with Western

cultures<sup>60</sup> (Ungar, 2008), '*han*' is deeply rooted in collective approaches to facing adversity and involves attention to interpersonal relationships geared to maintaining family harmony (Yang & Choi, 2001). Walsh, an American describing her own learning about resilience in the Korean context, understands '*han*' as 'suffering that is deep and yet not without hope' (Walsh, 2006:167-8). Despite differences arising from the individual and collective emphasis of personal relations in Western and Korean cultures Western ideas of resilience can contribute to an understanding of how Korean children cope with adversity. Masten's (2001) argument that resilience is common ('ordinary magic') is based on the findings of converging empirical studies that show resilience arising from the normative functions of human adaptational systems. In the Korean context, these systems are deeply embedded in the family, and for this reason, responses to the challenges experienced by the siblings of autistic children are likely to lie in the family and the willingness of the family to engage with specialist support systems that lie outside the family unit.

My findings suggest that Confucian values helped to promote resilience in the non disabled siblings of autistic children<sup>61</sup> by valuing the strength of family members banding together and helping each other (e.g. Lee, I. S. *et al.*, 2004). In this way the Confucian notion of filial obligation acts as a source of resiliency among Korean children (e.g. Hwang & James-Roberts, 1998). Moreover, Confucianism emphasises the value of sacrifice for each other and the significant contribution of loyalty to the resilience of family that, in turn, provides a stable environment for the children in the face of stressors (Wong, 2004: 107). Consistent with American studies of ethnic minority children (e.g. Zhou & Bankston, 1998; Stanton-Salazar & Spina, 2000), my study suggests that children's resiliency is rooted in adherence to traditional values and in support systems emanating from family ties.

The resilience shown by the children in this study, which might be termed 'honourable silence' is associated with the achievement of family harmony and maintenance of

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<sup>60</sup> Western research on resilience (e.g. Howard *et al.*, 1999; Luthar *et al.*, 2000; Rutter, 1993) argues that resiliency is not a stable, inherent personal characteristic but a competence achieved in an interactional process of a child and his/her developmental context (e.g. Howard *et al.*, 1999; Luthar *et al.*, 2000; Rutter, 1993).

<sup>61</sup> For example, J1 (see page 184), A1 (see page 185), refer to the continuing challenging behaviour of their autistic siblings, and their adaptation to accept this as part of ordinary life

family honour, achievements that bring both satisfaction and pride to the children (see section 7.2.4) and are perceived to compensate for the threats to well being posed by their roles in helping to care for their autistic siblings. The crucial argument is that individual achievement, associated in this study with resilience to adversity, is only of importance to the individual in as much as the whole family benefits. As Hwang (1997-1998:28-29) explains the Confucian value of harmony: 'when one is conflicting with someone else within his or her social network, the first thing one has to learn is 'forbearance' - giving up one's personal goal, for a prior consideration of maintaining harmonious relationships'.

By contrast, a children's rights perspective<sup>62</sup> would suggest that the strong filial obligations that characterise Confucian familism might lead to the oppression of children, particularly those facing unusual levels of responsibility such as the support of an autistic sibling. However, exploration of the literature on resilience in different cultural contexts suggests that the development of resilience is commonplace and cannot simply be equated with responsiveness to oppression. The important question arising from my study is how children's resilience can be acknowledged and valued at the same time as extending the notion of children's rights in the context of Confucian familism.

My study found that the children's 'voicelessness' (Wyness, 2000), is associated with sacrifice and the maintenance of harmonious family relationships, derived from the dominant cultural values, norms and meanings of 'being a good sibling'. The children in my study expressed reluctance to discuss their concerns with their parents, in part because they felt their parents did not listen, in part for fear of engendering 'disappointment'. They were also unwilling to talk to their friends who they felt would not understand their concerns. I argue, therefore, that although the children displayed a sense of harmony within the family and in public, they privately regarded themselves as invisible, with no place for the legitimate expression of their feelings, thoughts or questions. Their voicelessness also resulted from being expected to take 'second place' to maintain family harmony whenever there were tensions between their needs and those of their autistic siblings.

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<sup>62</sup> Commonly understood to be based on Western values of childhood (see page 11)

The question of 'competing needs' is also raised in the context of Western literature about 'young carers' who are described as being denied their needs as children (e.g. Aldridge & Becker, 1996a: 68). Olsen & Parker (1997), however, argue that the notion of competing needs of disabled parents and children might be controversial, with uncertainty about the weight of priority given to the children's caring roles and to the children's own needs.

In contrast, the high cultural value placed on children's contributions to their families in the Korean context (see section 9.4) serves to avoid focusing attention on threats to wellbeing. Consistent with Woodhead's (1997) argument, that children's needs are constructed by a shared normative framework of cultural values and practices, my study suggests that the voicelessness of siblings is viewed quite differently in different cultures. Despite the negative effects of long periods of silence in families (McHugh, 2003), my findings illustrate that 'voicelessness' is part of the normative expectations associated with accepting second place, an honourable act that helps to maintain family harmony. This presents a further paradox in which cultural reinforcement of sacrifice as honourable serves to mask the threats to the wellbeing of siblings of autistic children (see Lee M.H. *et al.*, 2004). This contrasts with recent developments in Western studies that have begun to focus on constructing children's voices (e.g. James & Prout, 1997; Prout, 2001).

I argue that failure to develop an awareness of the threats to the well being of siblings of autistic children maintains a status quo that values the benefits of sacrifice during childhood without addressing the 'costs'. It is therefore important to deconstruct the taken-for-granted aspect of children's contributions that form part of the normative expectations of siblings of autistic children. As with earlier studies (e.g. Harris, 1994; Meyer & Vadasy, 1994, Seligman & Darling, 1997; Powell & Gallagher, 2005), I identified threats to well being that, arguably, place the children in my sample at a significant disadvantage compared with their peers who do not have disabled siblings. I address each in turn.

First is parental inattention arising from high levels of attention placed on autistic children, with the result that siblings were expected to manage daily life alone and to have higher level of responsibilities. A common finding for Western and Korean families of disabled or chronically ill children is that the siblings are at increased risk of emotional and behavioural problems (e.g. Pit-ten Cate & Loots, 2000; Stoneman, 2001; Kaminsky & Dewey, 2001; Sharpe & Rossiter, 2002; Naylor & Prescott, 2004; Lee M.H. *et al.*, 2004; Yang, S.M., 2003; Sung, *et al.*, 2005; Honey & Halse, 2006). Consistent with these studies, siblings in my study expressed negative emotions such as loneliness, boredom, insecurity and anxiety arising from high parental expectations of tolerance and understanding; and a sense of unfairness and resentment at differential parental treatment within the family. In Western studies, the development of attention-seeking behaviours to counteract parental inattention may be a child's way of showing their unfulfilled need for nurturance (Greenspan, 2001 cited in Barr *et al.*, 2008:22). However, in my study the siblings were expected to accept parental inattention, directly influenced by traditional values involving children's unquestioned obedience, disapproval of behaviour that draws attention to the self, and discouragement from expressing their own opinions, especially when their ideas differ from [their] family" (Farver *et al.*, 2000:588).

Second is siblings' need for information about autism and its implications through the life course. The siblings in my study had little opportunity to obtain information about autism as a condition or its long term impact. Western literature (Meyer, 1993; Powell & Gallagher, 2005; Seligman & Darling, 1997; Harris, 1994), points to difficulties experienced by siblings and their parents in accessing sources of accurate information. Seo, H.J. (1994), also found that 51.5% of Korean parents of autistic children believed that autism would be 'cured' in the future, and argued that this belief could be due both to a lack of information and to the influence of religious beliefs. It is arguable that there is an even greater need for age-appropriate information for siblings of autistic children than their parents because of the close identification between and, in the Korean context, responsibility for, siblings. Tozer (1996) and Carol & Mikelle (1997) have made similar arguments in the UK and Australian settings respectively.

Third is the negative impact on school work. Although there is no conclusive evidence that high levels of children's care responsibilities lead to educational under-achievement (see Aldridge & Becker, 1993b; Thomas *et al.*, 2003; Dearden & Becker, 2000; 2004; Robson *et al.*, 2006), the children in my study were at times unable to concentrate on their school work at home as their autistic siblings continually disturbed their attempts to study, and they received little support from their parents with school work. In comparison with Western studies (e.g. Strohm, 2002; McHugh, 2003; Naylor & Prescott, 2004; Powell & Gallagher, 2005), my study found that the siblings felt more conscious of parental pressure to achieve educationally to compensate for the limitations of their autistic sibling. Although this does not mean that the children in my sample had serious problems with regard to academic ability, it does imply a potential for academic underachievement that left the children at a disadvantage in the Korean context in which academic success is seen as a high priority. Academic achievement is culturally valued, seen as the key to financial security, and a reflection of, and on, family status in Korea (Yang & Retting, 2003:354). The priority given to education and strong motivation for achievement are family affairs, because they are directed towards the prosperity of the family and towards maintaining its reputation (Kim & Hoppe-Graff, 2001:87). Adversely, a child's poor academic achievement in school is interpreted as the result of laziness or parental failure (Kwon, H.S., 2005). Lack of attention and support for the siblings' academic work could be seen as abandoning them to failure, because sacrifice and support provided by parents are regarded as essential ingredients for children's success in Korea (Kim & Park, 2006). In particular, this finding exposes the lack of access to additional schooling for the children associated with financial constraints placed on the family by the high cost of private services for the autistic siblings.

Fourth is the question of safe personal space. Consistent with Western-European literature (e.g. Miller, 2001; Doyle & Iland, 2004; Benderix & Sivberg, 2007), my study found that the siblings were not able to control the impulsive and uncontrolled behaviours of their autistic siblings such as making loud sounds, crying, sleep disturbance, temper-tantrums, self-injurious behaviours, and unpredictable aggressive behaviours that threaten personal safety. In Australia, Ross & Cuskelly (2006) found that 84% of siblings (ages 8–15) reported physical aggression by their autistic brother or sister, which provoked feelings of anger. In my study, physically aggressive behaviours

could make the children feel insecure and anxious at home and they were in a semi constant state of readiness to withdraw from, or lock themselves in, a room away from their autistic sibling. Although aggressive, disruptive and destructive behaviours have a significant impact on the family, the safety of siblings in the home was consistently overlooked by parents who appeared little concerned about the safety of their normally developing children.

Fifth, it was clear from my study that autism in the family causes financial difficulties due to the high cost of private special education and therapies in Korea. There is other convincing evidence that the Korean families of disabled children are more likely to be disadvantaged financially (Chung *et al.*, 2001; Oh & Jun, 2004; Byun *et al.*, 2006b; Chung & Han 2005). The additional direct living costs due to disability increased from 62.1% in 2000 to 67.4% in 2005 (Lee, S.W., 2005). In the U.K, the annual cost of caring for people with autism was estimated at more than £1 billion (Järbrink & Knapp, 2001). The strong association between autism and poverty contributes to increased social exclusion not only of the autistic child but also his/her family. Current evidence from Youn, J.S. (2007) also demonstrates that 88.4% of all school-aged disabled children and 91.6% of preschool disabled children had private special education or therapies. 38.7% of these families paid 300,000 Korean won (approximately £150), 25.9% paid 500,000 won (approximately £250), 20.9% paid 1,000,000 won (approximately £500) per month for private special education<sup>63</sup>. However, cash benefits in Korea (70,000 'won' (£35) per month) for disabled children were only granted on the basis of strict criteria: a 1<sup>st</sup> class (most severe) disability and a low-income family (Yoo, D.C., 2005). Previous studies (e.g. Choi & Choi, 2006) have stated that financial assistance makes only a minimal contribution towards effectively reducing poverty for the families of disabled people. None of the families in my study received financial assistance from the State. Poverty associated with autism is highly likely to continue to affect the lives of the children in my study as they assume financial responsibility for their autistic siblings in the future. Under social welfare policies influenced by Confucian familism, that take family contributions 'for granted', my findings offer further strong evidence that the families of disabled children are likely to be classified as having a lower socio-economic status in Korea (Kim & Kang, 2003).

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<sup>63</sup> 10.4% of families paid under 100,000 won but 4% of families paid over 1,000,000 won

Sixth, despite the range of visible/invisible ‘threats to well being’, only four of the children in my study attended a support group and none reported any involvement with additional support services. The four children attending sibling support programmes reported positive benefits similar to those mentioned in existing literature (Chun, H.I., 2001; Evans *et al.*, 2001; You, H.K., 2002; Dyson, 1998; Burke, 2004; D’Arcy *et al.*, 2005). In particular they valued friendships with children in similar situations, the information they received, and the opportunity to take part in activities which provided some ‘fun’ in their lives. Nevertheless, I found that sibling support groups were not accessible for all children and offered limited information. Moreover, some support groups were thwarted in their aims to increase self-esteem and improve the quality of children’s lives since mixed groups (age and gender) discouraged participation. These findings suggest that the children were caught in a ‘double bind’ because of a) the lack of institutional social support networks for siblings in families that regard autism as a private family matter; and b) the exclusionary impact of negative stereotypical attitudes towards autism. In particular, the stigma associated with being ‘disabled’ seemed to contribute to the low level of social support for families and siblings of disabled children, as reported in both Western and Korean literature (Seo, H.J., 1994; Lee & Kang, 1997; Meyer & Vadasy, 1994; Ratcliffe, 2003; Dodd, 2004; Naylor & Prescott, 2004; Burke, 2004).

## 9.7. Summary

In this chapter, I have discussed the everyday lives of children with autistic siblings in a Korean, Confucian familist, context. Figure 9-2 shows how:

Korean socio-cultural values give rise to both positive and negative influences on the experiences of siblings of autistic children.

Strong collectivist family values combined with negative attitudes to disability (autism) create the conditions in which services to support the families (including siblings) of disabled (autistic) children are under developed.



The highly regarded and embedded cultural norms of sacrifice, and filial obligation encourage siblings to assume significant responsibilities for the care and support of their disabled siblings.

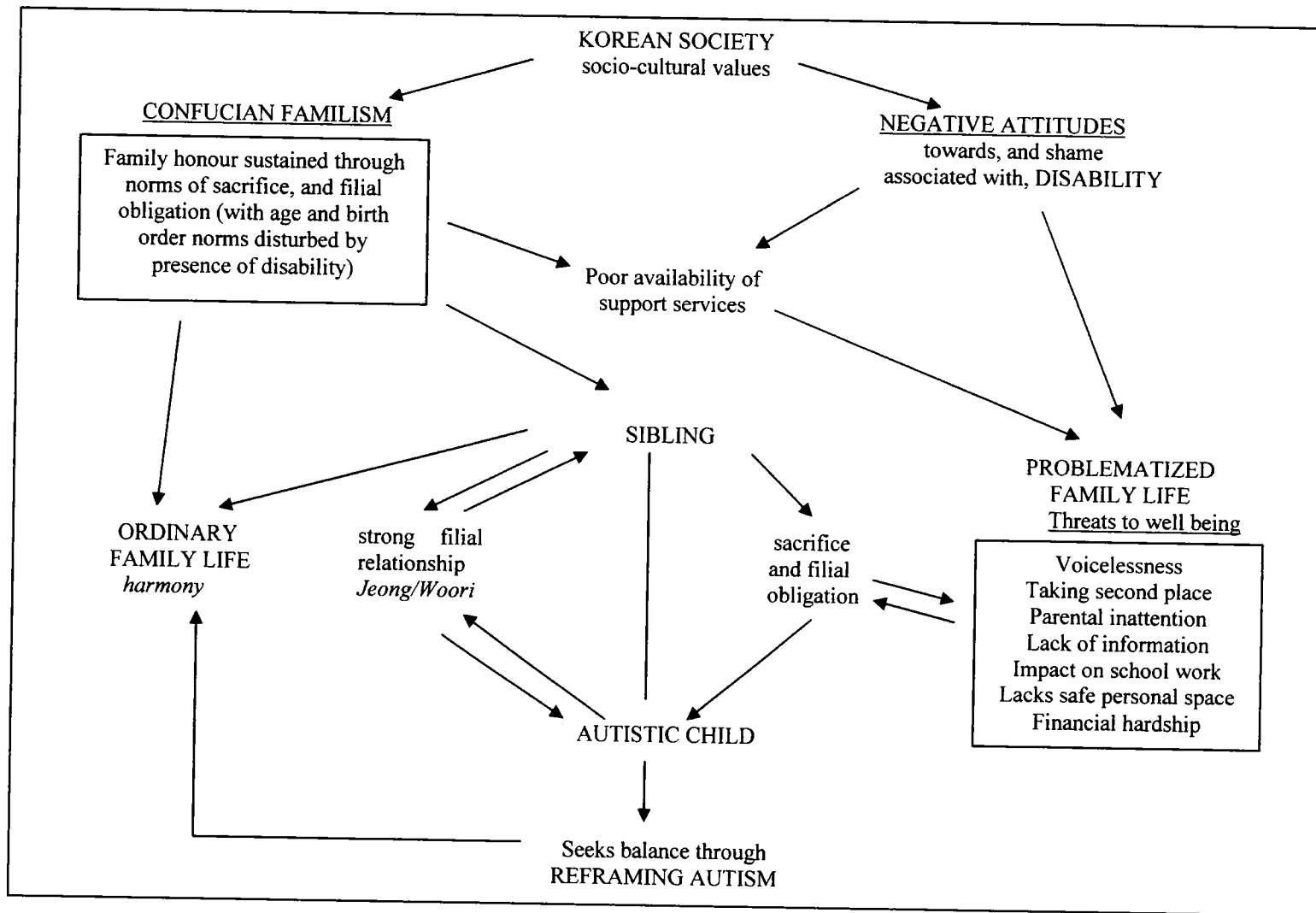
On the other hand, negative societal attitudes give rise to and reinforce a series of threats to wellbeing that in Western cultures might be defined in terms of 'stress' or oppression.

But while the 'sacrifices' made in undertaking these responsibilities are associated with a series of threats to well being, the children develop strong relationships with their autistic siblings through the development of '*Jeong*' and '*Woori*' that form the basis for relationships between the siblings and relationships of collective belonging or 'togetherness'.

The development of these strong bonds facilitates a positive reframing of autism and a sense of balance (harmony) in their daily lives with their autistic siblings in such a way that the siblings conceptualized their (unusual or 'strange') experiences as ordinary or 'familiar'.

My overall argument is complex in that I draw attention to the value and importance of the daily realities of non disabled siblings as both ordinary and extraordinary. The construction of ordinary daily life represents an affirmation of the strengths of the siblings of autistic children, although unacknowledged pressures on them threaten the long term viability of that ordinary life. Previous understanding and theories regarding siblings of disabled children focus on the complex and inconsistent effects of disability. I argue, however, that in the Korean context, focussing on 'ordinary daily life' offers a more nuanced understanding of the experiences of siblings.

**Figure 9-2** Model of The Influence of Cultural Values on The Identities and Daily Lives of Siblings of Autistic Children



## **Chapter Ten**

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## **Conclusion**

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## 10.1. Introduction

Through the video diaries and home movies of nine siblings of autistic children, together with i) reviewing sessions between children and the researcher and ii) interviews with parents, I have documented experiences of Korean siblings of autistic children in ordinary daily life. The study develops theoretical understanding of the impact of autism on siblings in a context of Korean Confucian familism that is characterized by particular cultural values, norms and beliefs.

This chapter summarizes the findings in relation to each of the research questions and revisits the theoretical approaches introduced in Chapters One and Two. The first section briefly addresses the findings and implications of this study; the second section shows the original contribution of this study; and the third section draws out reflections and implications of, and for, Korean policy and practice to ensure attention to and the inclusion of siblings. As discussed in Chapter Three, this is directly related to the Korean *Welfare of Disabled Persons Act* (MOHW, 2005). The final sections offer reflections on the experience of undertaking this study and include methodological considerations and implications for future research.

## 10.2. Summary of the Main Findings and Theoretical Implications

The central questions of this thesis are: i) What does it mean to be the sibling of an autistic child in a Korean context? ii) How do these children experience and portray their autistic siblings? iii) How do these children experience the impact of autism on their daily life in their family? iv) How do these children experience the impact of autism in wider Korean society? v) How do these siblings express their own vulnerabilities?

The first question, what it means to be the sibling of an autistic child in a Korean context, is addressed in Chapter Five where I argue that being a sibling of an autistic

child carries significant practices of sacrifice<sup>64</sup>. In everyday life, ‘unavoidable’ sacrifice is related to a strong sense of filial obligation that extends across the life span of both autistic and their siblings. There is no doubt that the identity of siblings is overwhelmingly rooted in the values of Confucian familism. In particular, ‘being’ a sibling is embedded in socio-cultural beliefs and traditions that are integrally related to practices shaped by predetermined expectations of what a good sibling is. The study shows that the lives of siblings of autistic children cannot be adequately understood or explained by reference to existing theory that is predominantly based on Western social psychological and young carers’ perspectives. The children’s sacrifice for their autistic siblings is valued and practiced as part of ordinary everyday life in a context of Confucian familism. However, the normative expectations associated with gender and birth order are disturbed by the presence of autism. Sisters and younger siblings who have older autistic children struggle to accept these contradictions. Some expressed resentment and a sense of unfairness, but accepted their ‘different’ filial obligations and some expressed pride in their ability to support their autistic sibling and, in turn, their parents on a daily basis.

Chapter Six presents the siblings’ experiences and portrayals of their autistic siblings and their relationships with them. In contrast to social psychological perspectives which generally claim a range of ‘negative’ or ‘positive’ impacts of autism on siblings, my study found that the relationships between autistic children and their siblings is seen as any other sibling relationship, characterized by a strong sense of *Jeong* and *Woori* grounded in Korean cultural norms. By expressing and practising these basic values, they maintain strong relationships with their autistic siblings.

Thus, siblings in this study did not view autism as a tragic condition, but rather reframed autism as a different way of being a ‘brother or sister’, rather than an ‘autistic brother or sister’. Interestingly, as is clear from the visual data and reviewing sessions four children understood autism as a temporary condition from which their siblings could recover. This helped them focus on what their autistic siblings could do, rather than on what they could not do. They depicted positive ways in which they have come

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<sup>64</sup> Contributing or giving up for the sake of something that is of greater value or importance (see glossary for fuller definition)

to see autism, their relationship with their autistic sibling as ‘sameness’, doing joint activities, effective communication, and the development of *Jeong* and *Woori* in line with traditional values of siblinghood. Despite focusing on the positive aspects of siblinghood, the children acknowledged ‘difference’ in their relationships with autistic siblings linked to autism.

In spite of the modern influences of individualistic familism, encouraged by globalization this study shows that the core values of interpersonal relationships implied by Confucian familism remain strong in Korean sibling relationships between autistic children and their siblings.

Chapter Seven presents the children’s experiences of family life and their lives in the wider community and society. In common with studies from the West, I found that the presence of an autistic child in family makes daily life less predictable and requires constant negotiation and flexibility. However, although all siblings in this study have experienced challenges in confronting stressful situations, they continuously strive to seek a sense of balance in order to achieve ongoing harmonious family life reflecting Confucian principles of family value. The construction of harmony in the children’s daily lives is reflected in their perceptions of ordinariness in the family. Moreover, this study illustrated their empathic responses toward their parents’, especially mothers’, predicament. The active sharing of responsibility for the care of autistic children not only relieved their parents of some caregiving activities, but also helped to improve understanding of, and relationships with, their autistic siblings and parents. Although these findings bear some resemblance with the findings of Western studies that focus on ‘young carers’, it is clear that the Korean children in my sample do not depict themselves as young carers, but as brothers or sisters fulfilling the obligations associated with family life.

In wider society, this study found that the children faced societal barriers and obstacles created by public responses to autism reflecting negative and stigmatizing cultural attitudes to disability. However, the children developed their own interpretations of autism in ways that focused on the positive and the ordinary as well as the challenges presented as a result of socio-cultural stereotypes.

The children's views contrast with traditional Korean cultural views (articulated by adults) by focusing on the 'familiarity' of their siblings' autism rather than its 'strangeness'. In this way they develop capacity to adapt to the changing condition and challenges presented by their siblings' autism. They also found ways of integrating worlds of 'disability' and 'ability' to articulate realistic representations of their everyday lives with their autistic siblings. These representations include understandings of autism focusing on ability and 'recovery' rather than limitation and 'life-sentence' or tragedy and are useful in understanding children's day-to-day family and wider social lives. But despite their focus on 'ordinariness', they were also exposed to a variety of challenges and limitations as a part of ordinary daily life.

Chapter Eight focuses on a series of vulnerabilities that threaten the children's well being, although these are effectively masked by the children's own emphasis on the 'ordinariness' of their daily lives. An underpinning threat to well being lies in the children's 'voicelessness' that arises from their acceptance of, and adherence to, normative expectations of 'being a good sibling' and maintaining harmony in a hierarchical family system. This involves willingness to 'take second place' to their autistic sibling who is at the centre of the parents' attention. The children downplayed or hid their own priorities. It was very difficult for the children to highlight their concerns or needs when they saw that other family members, especially their parents, were stressed. My study found, however, that the children did articulate a desire for more parental attention, age-appropriate information, support to improve their educational achievements and safe and secure space at home. In addition it was clear that the financial demands associated with supporting an autistic child left the family with financial constraints that diminished opportunities for their siblings. Similarly, there were few formal support services to address threats to the well being of the siblings of autistic children.

### 10.3. Contributions of This Thesis

This is the first study using visual ethnographic methods to explore the daily lives of siblings of autistic children from their own perspectives. The insights offered by this study show that cultural expectations associated with Confucian familism remain powerful in taking priority over individual experiences, desires and needs. It is not only personal experience that matters in the children's daily lives, but also their culture that plays a crucial role in influencing their approach to daily life. This study challenges the theoretical tenets of much research on siblings of disabled or chronically ill children, that have focused predominantly on social psychological perspectives. Culture offers a means for interpreting sibling identities, relationships and daily lives (see Weisner, 1993b; Cicirelli, 1994). And in the Korean cultural context this study has contributed to the understanding of siblings of autistic children in a system of Confucian familism with particular beliefs and values that have (largely negative) implications for families with disabled children. The knowledge gained from this study offers new insights that can support the design and development of culturally-sensitive support services for the families of autistic children.

The thesis also challenges current approaches to the study of siblings of disabled children that continue to conceptualize siblings of disabled children primarily as 'vulnerable' and negatively affected by disability. This study provides an alternative vision of siblings growing up in 'ordinary' as well as 'extraordinary' ways and achieving harmonious family life. Through the lens of 'ordinariness', siblings were able to reframe autism in ways that minimized any negative effects on their daily lives and gave them positive hope for recovery in the future. In this way the study offers insights into the lived experiences of Korean siblings of autistic children.

Methodologically, this study shows that working with children as researchers produces self-representations and self-reflections through visual ethnography, leading us to knowledges that are never spoken. The video materials convey a wealth of abundant information depicting the children's everyday lives in ways that are credible and valuable. Although I do not claim that visual ethnography is the perfect method for generating children's experiences and understandings, it is a very powerful tool that



allows them to show, express and discuss their own experiences and interpretations of daily life. In particular, it can capture a broader and deeper range of children's perceptions and experiences than reliance on the eyes of an adult researcher. Moreover, the video diaries and home movies used in this study have practical value in contributing to a better understanding of children's lives, highlighting hitherto unknown features of significance to them.

## **10.4. Implications for Korean Policy and Practice**

### ***10.4.1. Invisibility within the Social Support System***

Despite Korean government acknowledgement of the needs associated with disability (MOHW, 2005) and gradually increasing awareness about the roles played by, and the needs of, siblings of disabled children in different parts of the world, there is no specific policy or legislation to underpin the provision of support services for the siblings of disabled children in Korea. Moreover, only few professionals have recognized the need for services for siblings of disabled children in Korea (e.g. Chun, H.I., 2001; Kim, S.H., 2004). In the West too, government systems have been slow to recognize the needs of siblings (Stanton 2000: 48).

Korean legislation focuses primarily on the concerns of disabled children as 'children with special needs for medical and vocational rehabilitation, and relieving financial burden'. But there is no documented awareness of the non financial needs of parents' or siblings'. Achieving recognition of the siblings of autistic children as being 'in need' is problematic in different ways: a) despite the *Child Welfare Act* (revised 2001) and the *Welfare of Disabled Persons Act* (amended 1999), disabled children are only considered to be children in need and external supports are only available once a family is officially identified as being at crisis point, something that would be a source of shame; b) the siblings of autistic children are in a paradoxical situation, experiencing positive cultural benefits from their roles as caring siblings as well as challenges – in the words of Miller (1996) they have been offered 'unusual opportunities and unusual problems'; and c) the honour derived from fulfilling their caring responsibilities can mask the identification of

their difficulties. As a result, particular efforts are required to ensure that siblings of autistic and other disabled children are heard, informed, supported and protected.

Since the economic crisis in 1997, Korean social welfare policy initiatives have been increasingly influenced by Western concepts of welfare (e.g. Shin, D.M., 2003; Shin & Shaw, 2003; Croissant, 2004; Holliday, 2005; Kwon & Holliday, 2007). The expansion of neo-liberal global standards has challenged the values of the Confucian welfare state and traditional family culture, in which 'relation-based welfare' (Hong & Song, 2006: 248) dictates that welfare is produced within, and provided by, the family.

Due to a rapidly changing family system caused by a low rate of fertility and an ageing population as well as the weakening of the extended family support system and increased female participation in the labour force (e.g. Shin & Shaw, 2003; Sung, S.R., 2003; Park Y.R., 2006) there is increasing need for support services in order to replace the traditional role of the family as caregiver. The number of community welfare centres for disabled people has increased by over four times, with 391 facilities in 2006 compared to 88 in 1990 (MOHW, 2006a). The government budget for disabled people has increased from approximately £172.5 million in 2004 to £329 million in 2007 (MOHW, 2006b).

Despite this increase in state provision, scholars have argued that 'family-based welfare provision' is still prevalent<sup>65</sup> (e.g. Holliday, 2005). My findings also suggest that, although Korean society today is not as strongly influenced by Confucian familism as in the past, some traditions remain strong, particularly with regard to family obligations and the care of disabled members. Shin & Shaw (2003: 339) comment that 'the moral policies of the family in Korea have been effective in legitimizing the absence and deficiency of public protection programmes for needy families and individuals, but not in alleviating family problems via the revitalization of traditional family structures or attitudes.' Strong moral virtues still impose heavy obligations upon the family. For example, the style of social welfare provision for disabled children has been reformed by increasing welfare state expenditures, but, as I have shown, the rationale of Korean

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<sup>65</sup> But other scholar have argued that the Korean welfare system have apparently changed into Westernized model of a welfare state (e.g. Ramesh, 2003; Kuhnle, 2007)

welfare policy for disabled children appears still to depend on family responsibility (e.g. Jang *et al.*, 2006). Ironically, although the traditional moral value of family obligation has become blurred, disabled children are still obliged to depend upon the full support of their family because there are few facilities for them in Korea.

Poorly developed welfare policy for disabled children is exacerbated by lack of attention to consideration of the development of social support provision for families. Shin & Shaw (2003: 337) note that 'there has indeed been a deliberate governmental strategy not to develop a supporting social infrastructure or a modern welfare state package of social services....such as might assist the elderly and their informal caregivers'.

Based on my findings, the strong moral values of familism and Confucianism that underpin the obligations of Korean children with autistic siblings are strongly associated with their invisibility and marginalization since the use of publicly provided services may be experienced as shameful and a sign of family failure to meet culturally prescribed obligations. This argument is consistent with the results of a cross-cultural study (Youn *et al.*, 1999), which concluded that higher cultural values for Korean caregivers made their daily life more difficult, especially in terms of emotional distress. Therefore, I would argue that current Korean disability policies fail to address hidden aspects of family life, and that the government continues to rely on cultural norms of family responsibility for disabled children. This presents a significant barrier to any public consideration of the siblings of disabled children.

Korean welfare policy stresses private responsibility. The value of the family has its roots in Confucian familist traditions, and inhibits public intervention, even in extreme cases (Kim, Y.H., 2003). As a result there has been no development of national policy frameworks to address the welfare needs of children who live with autistic siblings.

In Western welfare regimes attention paid to supporting families with autistic children focuses largely on the parents (especially the mother) and the children with autism, with little attention given to siblings. For example, the *EarlyBird* programme of the National Autistic Society in Britain aims to equip parents with knowledge and understanding of

how to enhance their autistic child's social communication and behaviour (Engwall & MacPherson, 2003: 13). But there is no explicit provision for including siblings in this programme. In the USA's *Son-Rise* programme (<http://www.autismtreatmentcenter.org>), there are no organized support groups for siblings of the autistic children taking part in the programme.

Despite the popular emphasis on the importance of a whole-family approach, support service provisions across the world tend to focus on disabled children or the parents, often neglecting siblings. Siblings have little, if any, input into service planning for the families, and the sibling's view within the whole family perspective appears to be overlooked.

#### ***10.4.2. Assessment Focus on Problems not Needs***

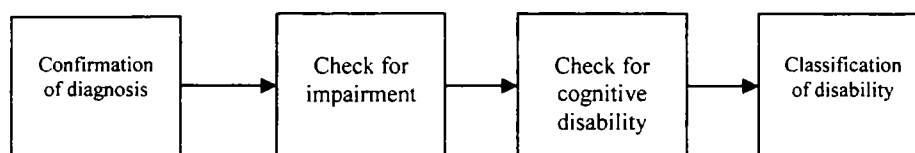
In a welfare context in which state support for families with autistic children is limited to the medical, and educational/vocational needs of the autistic child and the financial needs of only the poorest families, little attention is paid to the rights or needs of the siblings of autistic children. Article 45 of the *Welfare of Disabled People Act* (MOHW, 2005) states:

The central government and local authorities might pay the disabled children's care bill [*Jang-ae a-dong bu-yang su-dang*] to compensate additional costs due to disability, according to the carers' (a person with parental responsibility for a disabled child) financial status and the nature of the impairment.

Assessment of disabled children and their families is framed within a context of problems rather than needs, and much less 'rights'. Support services that do exist are accessed through identifying 'deficiencies' rather than identifying opportunities for 'empowerment'. In particular, assessment of disabled children focuses on responding to 'impairment' rather than 'needs', and thus fails to detect the needs of autistic children and other members of their family. The most important function of assessment for disabled children is to distinguish the nature and degree of their own impairment from a

diagnostic prescriptive standpoint, which is decided by a psychiatrist only (see Figure 10-1). It relies predominantly on a medical model, which stresses criteria of impairment.

**Figure 10-1** Diagnostic Assessment Procedure for Autism in Korea



Source: MOHW(2003) *Diagnostic Criteria of Disability*. p.46

However, assessment is not considered a ‘family matter’, although Article 5 of the *Welfare of Disabled Persons Act* (MOHW, 2005) declares an extremely rigorous family responsibility:

The family should encourage disabled people to participate in socio-economic activities using the abilities they have. The families of disabled people should support the independent lives of the disabled.

The Act focuses on the family’s responsibility for their disabled children but, significantly, fails to engage with the potential impact of childhood disability on siblings within the family and any unmet needs they may have. Previous studies in Western and Korean contexts have shown that having autistic children without support can have a negative impact on the family (Gupta & Singhal, 2005; Whitaker, 2002; Randall & Parker, 1999; Shin *et al.*, 2004; Lee & Kang, 1997). A literature review by Jeon & Kim (2005) suggests that although there is an understanding of the need for a whole family approach to assessment, there is, in reality, no support service provision for the whole family.

In Western literature, Burke (2004:115) argues that the needs of both disabled children and siblings should be identified within the scope of an assessment. In terms of the young-carer perspective, Dearden & Becker (2001:229) also note that ‘a whole family approach to assessment should ensure that all needs are taken into account and that service provision meets the needs not only of disabled parents, but also of their children’.

However, none of the nine families in my study had experienced assessment of the needs of siblings<sup>66</sup>.

In Britain too there is no particular national service strategy for the siblings of disabled children. But the *National Service Framework for Children* (DoH, 2000) states:

The quality of relationships between siblings may also be of major significance to a child's welfare. (p. 25)

Siblings may be affected significantly and services should address their needs  
(p. 58)

The NIASA has produced a '*National Autism Plan for Children*', which provides guidelines that hope to encourage transparent and efficient diagnostic processes able to meet the needs of autistic children and families that are not prescriptive but demonstrate good practice (NIASA, 2003: 9). This plan also recognizes that:

Particular consideration may need to be given to the future needs of siblings. This may be addressed through the core assessment carried out by social services. (p.40)

In Korea, however, assessment processes for disabled children are not consistently integrated in a whole family approach with the majority being orientated to the disabled individual. A government study (Seo *et al.* 2001) reports that only 30% of care facilities for disabled children in Korea include Individual Family Support Plans (hereafter IFSP), with most state and private agencies practicing 'individual' assessments. And the government 5-year disability project (see chapter 3 section 3.3.1), contains no clear tools or frameworks for assessment of the problems or needs of siblings and families of disabled children. This failure to recognize the needs of siblings leads to further marginalization. In the British context Burke (2004:116) has argued that needs assessments for disabled children and their siblings should be

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<sup>66</sup> One sibling had been referred to a psychiatrist for diagnosis as a result of her own behaviour problems. The family was responsible for paying for this diagnostic assessment and it did not lead to any state supported intervention.

considered independently but not separately, and that both assessments should include a holistic view to reflect the specific situation of the family.

#### *10.4.3. Adult-Centred, Supply-Led System*

Policy and support services for disabled children and families in Korea are designed and determined by adults and dominated by a supply-centred model rather than one that responds to the identified needs of children. This is problematic in a number of ways.

First, strict rules of eligibility for services lead to support being offered on the basis of specific medically defined categories rather than on the basis of demonstrable needs. Only the families of those with specific conditions listed in the legislation are eligible for registration and consideration for (financial and medical) support services. Unregistered disabled children and their families do not receive state support, while support for those who are registered is limited to financial benefits for the poorest families.

Importantly, these eligibility criteria do not consider the children's perspectives. There is no tradition of seeking children's perspectives in Korea and we must look elsewhere to assess the value of taking a more child centred approach. Interestingly, Western literature refers to tensions between a child-centred and a whole family approach to the needs of families with disabled children. And the evidence suggests that even when a whole family approach is taken, the focus is often on the disabled child and parents, with little attention given to siblings (Connors *et al.*, 2004). The message here is that measures to address the needs of siblings of disabled children must either involve improvement in family centred approaches to give voice to siblings, or move beyond family centred approaches to ensure that their needs are considered in their own right.

Most family support for disabled children in Korea is in the form of training programmes, which focus on educational training for parents, especially mothers (Jeon & Kim, 2005). Such an adult-centred system has largely ignored children's opinions and perceptions. In particular, my study suggests that the only provision for addressing siblings' needs in Korea is through independent sibling support groups. Previous

literature also indicates that this type of support programme for siblings is a successful way of helping with siblings' needs (Meyer & Vadasy, 1994; Dyson, 1998; Naylor & Prescott, 2004; Dodd, 2004; Burke, 2004). However, in my study siblings only attended sibling support programmes when urged by their parents. Moreover, the groups that existed were limited in their popularity among the siblings. Although there were expressions of enjoyment of activities and the chance to discuss experiences with those in a similar situation, there were more expressions of dissatisfaction as a result of mixed gender and age groups. It is far from clear, therefore, that sibling support groups, as currently constructed, are likely to provide an entirely effective support service for siblings who may be reluctant to attend such programmes. Strohm (2002) has argued further that siblings may be reluctant to seek support because they feel that their problems are not significant in comparison to those of their brother or sister, and because they do not want to add to their parents' stress.

In addition to being adult-centred, the Korean social support system can be identified as a 'supply led' (Kim, Y.D., 2005b; Kim, S.H., 2007). The assessment process and access, as well as decision-making, are still predominantly the responsibility, and within the control of, professionals with little participation or involvement of service-users.

There is evidence of early stage reform in Korea with the *Disability Discrimination Act* 2007 being more informed by a disabled person-centred perspective and human rights, and the introduction of anti-discrimination provisions in relation to employment, education, information access, electoral rights, barrier free environment, public facilities, gender and legal services.

The negative impact of the 1997 financial crisis on the capacity of families to support their own dependent members led to reforms in welfare policy and increased state expenditure (Aspalter, 2006:294), although this has been directed at funding the private and voluntary sectors to provide welfare services (Hong & Song, 2006) and there is heavy reliance on the private or voluntary sectors for the care of disabled people. These services operate on a fee-paying basis, with management costs compensated by central government or local authorities. Despite this change in direction from family based to organizational support services, there has been no accompanying shift to recognize the centrality of the service user in the design and use of services (Kim, Y.D., 2005b).



Limited available research on sibling support services also indicate that processes are dominated by service providers who continue to operate a supply-led rather than a user-centred approach (Chun, H.I., 2001; Lee, S.H., 2003).

Western literature has emphasized that support services should involve all relevant professionals (e.g. school teacher, psychologist, social worker) in order to address siblings' needs and interests (Dyson, 1998). No such developments with other providers have been developed in sibling support groups, locally or nationally, in Korea. None of the siblings in my study had ever been supported by any specialist professionals (e.g. therapist, social worker, doctor or psychologist). As a result, sibling support programmes tend to be operated by only a few professionals (e.g. social worker, special education teachers), and are temporary or vacation programmes. I would claim that this supply-led system is associated with the limited effectiveness of existing sibling support programmes.

#### *10.4.4. Summary of Implications for Korean Policy and Practice*

This study is the first, in a Korean context, to explore the experiences of siblings of autistic children who were 'given voice' (Grover, 2004) through the use of video diaries and home movies to articulate their experiences and understandings of daily life with autistic siblings. The findings indicate that the culturally normative roles of non disabled children in supporting their autistic siblings on a daily basis easily equates to a lack of recognition, by family or the state, of the support needs of non-disabled siblings. This lack of recognition lies at the heart of this thesis and is addressed in a number of recommendations for health and social welfare policy makers in Korea. These recommendations are consistent with articles 29 and 30 of the UNCRC that focus on the application of children's rights within children's own cultural contexts<sup>67</sup>:

- To acknowledge the contributions and responsibilities of non disabled siblings

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<sup>67</sup> In the English context, article 29 of the UNCRC (education should develop each child's personality, talents and abilities to their fullest potential, as well as develop respect for parents, other members of human society, and the environment) and Article 30 (right to use language, religion and customs of family or group) are cited as means of 'making a positive contribution to the community and to society' as part of 'Every Child Matters' (UNICEF, 2007)

in caring for autistic children, particularly the caregiving roles associated with being a sister and the long term responsibilities associated with being the eldest son. (Chapter 5, 6, 7)

- To develop public education about autism and reduce the associated social stigma (Chapter 7)
- To acknowledge the additional costs (including financial costs) to families in raising autistic children (Chapter 8)
- To acknowledge and address the support needs of siblings of autistic children. (e.g. locally available, age appropriate counselling, therapy services, education and leisure facilities ) (Chapter 8)

## **10.5. Agenda for Future Research**

### ***10.5.1. Implications of Limitations of the Study***

In this thesis, siblings have been placed at the heart of the research as a strategy for gaining the closest possible insights into their everyday life experiences. Through the use of video techniques the children provided visual data to illustrate what they felt were salient aspects of family life. This approach was not without challenges.

The challenge lay in ensuring that the children were able to retain control of the PMP for the full two weeks of the data collection period. I expected that many Korean children and adolescents may already be familiar with visual methods, and interested in the activity of video-making. However, I cannot be entirely certain that their choices for filming reflected their own choices and priorities. In reviewing sessions, four children (Cases 1, 5, 6, and 7) indicated that although they consented freely to take part in the study they felt bound by a sense of honour and by a sense of duty to 'obey' their parents, some of whom (Cases 6 and 7) continually reminded them to film on a daily basis, to complete the task.

Other limitations arose from the use of video diaries. Noyes (2004) indicates that video diaries as a technique are worthwhile only with teenage children, whose level of

competency and cognitive skills are more suited to the medium. In my study the seven children aged twelve and over offered longer, richer, more analytic and interpretative accounts of their daily experiences than the three children of seven and eight who recorded less frequently, for shorter periods and offered simple descriptions of events. Moreover the three younger children expressed more interest in 'acting' in home movies rather than using them to offer their own lens on everyday life with their autistic sibling.

The second challenge was in the quality of the visual data. At first sight, it may seem that visual methods allow children to record happenings in their everyday life that may have been lost by using other research methods. Although this study was designed NOT to have rules regarding the content and length of the children's videos, there is an ever present danger that children may generate data that cannot be used. This happened in two cases where one film of one child contained no visible content and another child on one occasion left the PMP player simply recording a television programme. Fortunately, these two children generated alternative, useful, visual data. Such problems are not confined to child participants of course and in addition to keeping in continuing contact with co-researchers as I did in this study, I would also either visit to check or ask that participants check the quality of the video footage they are recording in order to identify and correct technical errors at an early stage.

No technical gadget is without its problem. Although PMP players are very convenient, I struggled with several technical problems including battery life, brightness and sound. And in particular, late start-up time and shutter lag speed mean that children cannot record an important scene immediately. But this is hardly surprising, as all current digital gadgets are still struggling with these problems that can be addressed by continually upgrading equipment to obtain the highest quality results possible (Walsh *et al.*, 2007).

As with much qualitative research my study faced the common challenges presented by having a small number of participants. It must be stressed that the sample is NOT representative of Korean siblings as a whole, not only because of its small scale but also because of the snowball sampling strategy employed (Bryman, 2001). The participants

were recruited from two particular community sampling frames (parents' groups), without differentiation of the severity of the autism, social status, region and family size.

A further challenge is that, as a Korean person, I may have failed to be sufficiently aware of the distinctiveness of Korean cultural values that form part of my 'unconscious being' having been brought up with, and immersed in, those values. Over-familiarity with a particular culture may lead to challenges in articulating cultural values and may lead to failure to reveal different and alternative meanings and interpretations of the data. I took measures to address this particular challenge by: i) familiarizing myself with Foucauldian theory that informs how particular views of the world are generated (Foucault, 1997), ii) accessing a range of studies that address the challenges in making the familiar strange (e.g. Kaomea, 2003; Harwood, 2006) and iii) continuous critical debate and engagement with my supervisors and with other overseas PhD students also studying social phenomena in their own cultures.

Finally, certain Korean words, phrases, concepts and metaphors cannot easily be translated adequately into English (see Donnelly, 2001) and there is a risk of losing the subtle nuances and meanings when there are no-equivalent words or expressions. For example, no equivalent word or expression for *Jeong* exists in English which approximates most closely with 'strong interpersonal (often filial and affective) ties'. Moreover, there are significant differences in language structure. For example English has well-developed relative pronouns, but Korean has no relative pronouns. Therefore, a sentence with a relative pronoun makes translation difficult. In order to address these challenges I focused on seeking equivalent meanings of words rather than simple translations and used a process of intellectual negotiation with supervisory and other colleagues (Eco, 2003) to achieve equivalence of meaning rather than maintenance of linguistic structure.

### ***10.5.2. Implications for Future Research***

The findings of my study (relating to the experiences of children living together with their autistic siblings in Korea, and what this means for Korean welfare policy)

highlight areas where we lack knowledge, and which offer rich opportunities for further research.

First is the question of whether the insights from this study of the siblings of autistic children in Korea can provide useful insights for other types of disability, in other Confucian familist cultural contexts, in rural as well as urban areas, in situations where disabled children and their siblings do not live in the same household, and across socio-economic groups. My study has highlighted the fundamental importance of cultural values in understanding the experiences of siblings of autistic children and their families, underlining the need to generate culturally-sensitive knowledge about the experiences of siblings. It is also important to stress that the study focuses only on siblings who are children and adolescents. The experiences of adult siblings of autistic adults have not yet been explored, and longitudinal studies of sibling experiences would provide valuable insights into the relationship between expectations during childhood and experiences in adulthood. For example, two sisters and one brother in my study expressed clearly the view that they would only marry partners who were willing to share responsibility for the care of their autistic siblings. A longitudinal study would best illuminate the relationship between childhood expectations and adult experiences, but a retrospective study of adult siblings might also offer insights into this relationship and offer better understanding of family obligations in the rapidly changing socio-political context of Korea.

Second, a recurring research theme throughout this study has been the persistent strength of filial obligation among the siblings while the autistic children were 'relieved' of their filial obligations. We must not assume that relief of filial obligation applies across other types of disability and a study of the experiences of siblings of children with e.g. mobility or sensory disabilities may yield different results. The term 'young carer' is not recognized in Korean welfare policy. Filial piety and '*being* a good sibling' embody behaviours not only showing respect and obedience, but also undertaking a range of tasks including those associated with accompanying, befriending, and practically helping siblings, differentiated by gender and birth order. The Western concept of 'young carer' (broadly defined as children taking responsibility for activities usually carried out by parents, and developed in political contexts that have paid explicit

attention to the notion of children's rights) lies uneasily in a cultural context associated with filial piety. Although Korea became a signatory to the UNCRC in 1991 explicit attention to children's rights has focused on obedience for parental authority rather than respect of children's voices (MOHW *et al.*, 2005: xi). Future research could usefully focus on the range and prevalence of caring by child aged siblings in different cultures, as well as different cultural understandings, meanings, and implications of such care.

Third, it may be useful to focus on reciprocity between non-disabled and disabled siblings. The autistic children were not the focus of this thesis that concentrates on illuminating the effects of autism on siblings in the family. Sanders (2004) has argued that such an approach "may well be colluding with a perception of disabled siblings as more broadly 'less able' by virtue of their disability, a disempowering view" (p. 128). And Priestley (1999) has also argued that "they [disabled children] are also social actors, responding to discursive practices, resisting and reconstructing them to fit their own experiences and priorities." (pp. 93–94). In the language of social work, such an approach runs counter to the 'strengths-based' perspective (Saleeby, 2005). A focus on reciprocity could also provide a more balanced approach to children's rights that are the domain of disabled children as well as their non-disabled siblings.

## 10.6. Final Remarks

Within the Korean context, autism is not only a source of significant challenge to all family members, but creates a unique set of complex experiences for siblings who must negotiate a path through life that lies outside commonly prescribed cultural values, norms and expectations. Nevertheless, I end this thesis by questioning why the literature consistently focuses on 'difference' in theorizing and researching the lives of siblings with disabled children. Ultimately, I believe that this study provides one of the first attempts to offer a more balanced understanding of the ordinary life experiences of children, experiences that have commonly been overshadowed by the predominant focus on the disability of their siblings. Although the findings are based on only nine Korean children, they have central relevance for, and can be drawn upon as a starting

point for, further examination to extend international understanding of the links between siblinghood and disability.

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## **Bibliography**

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- Akshoomoff, N., Pierce, K., & Courchesne, E. (2002) "The neurobiological basis of autism from a developmental perspective." Development and Psychopathology, 14(3) 613-634.
- Ahmad, W. I. U. (2000). Ethnicity, Disability and Chronic Illness. Buckingham: Open University Press.
- Ahn, B. S. (2002). A Study on the needs of the siblings of individuals with mental retardation. Dan-Kook University. MA Dissertation. in Korean
- Ahn, S. H., & Lee, S.C. (2005). The Development of the South Korean welfare regime. In: C.K. Wong, & A. Walker (Eds.) East Asian welfare regimes in transition: from Confucianism to globalisation. Bristol: The Policy Press: 165-186.
- Akhtar, S., & Kramer, S. (2004). Brothers and Sisters: developmental, dynamic, and technical aspects of the sibling relationship. Maryland, Lanham: Rowman & Littlefield.
- Alaszewski, A. (2006). Using Diaries for Social Research. London: Sage.
- Alderson, P. (2000). Children as researchers: the effects of participation rights on research methodology. In: P. Christensen, & A. James (Eds.) Research with Children: perspectives and practices. London: Falmer Press: 241-275.
- Alderson, P. (2001). "Research by Children." International Journal of Social Research Methodology 4(2): 139-153.
- Alderson, P. (2004) Ethics. In: S. Fraser, V. Lewis, S. Ding, M. Kellett & C. Robinson, Doing Research with Children and Young People. London: Sage. 97-112
- Alderson, P., & Morrow, V. (2004) Ethics, social research and consulting with children and young people. Barkingside: Barnardo's
- Aldridge, J. (2007a). "All Work and no play? understanding the needs of children with caring responsibilities." Children & Society Online Early Articles.
- Aldridge, J. (2007b). "Picture this: the use of participatory photographic research methods with people with learning disabilities." Disability & Society 22(1): 1-17.
- Aldridge, J., & Becker, S. (1993a). Children Who Care: inside the world of young carers. Loughborough: Loughborough University Young Carers Research Group.
- Aldridge, J., & Becker, S. (1993b). "Punishing children for caring: the hidden cost of young carers." Children & Society 7(4): 376-387.
- Aldridge, J., & Becker, S. (1994a). My Child, My Carer: the parents' perspective. Loughborough: Department of Social Sciences in Loughborough University.
- Aldridge, J., & Becker, S. (1994b). A Friend Indeed: the case for befriending young carers. Loughborough: Loughborough University Young Carers Research Group.

- Aldridge, J., & Becker, S. (1996a). "Disability rights and the denial of young carers: the dangers of zero-sum arguments." Critical Social Policy 16(48): 55-76.
- Aldridge, J., & Becker, S. (1996b). Caught in the caring trap: the health of children who care. In: P. Bywaters, & E. McLeod (Eds.), Working for Equality in Health. London: Routledge: 66-80.
- Aldridge, J., & Becker, S. (1998). The Handbook of Young Carers' Projects. London: Carers National Association.
- Aldridge, J., & Becker, S. (1999). "Children as carers: the impact of parental illness and disability on children's caring roles." Journal of Family Therapy 21(3): 303-320.
- Aldridge, J., & Becker, S. (2003). Children Caring for Parents with Mental Illness: perspectives of young carers, parents and professionals. Bristol: The Policy Press.
- Aldridge, J., & Wates, M. (2005) Young carers and disabled parents: moving the debate on. In: T. Newman and M. Wates (Eds.) Disabled parents and their children: building a better future. Ilford: Barnardo's. 80-99
- Alexander, V.D. (2001) Analysing visual materials. In: N. Gilbert. Researching Social Life. 2<sup>nd</sup> ed. London: Sage. 343-360.
- Ali, Z., Fazil, Q., Bywaters, P., Wallace, L., & Singh, G. (2001). "Disability, ethnicity and childhood: a critical review of research." Disability & Society 16(7): 949-968.
- Almeida, D. M. (2005). "Resilience and vulnerability to daily stressors assessed via diary methods." Current directions in Psychological Science 14(2): 64-68.
- American Psychiatric Association (2000). Diagnostic and Statistical Manual of Mental Disorders. Washington: American Psychiatric Association.
- An, D. Y., & Kim, B.S. (2005). "Siblings with disability and non-disability on social attitude of non-disabled siblings toward disabled one." Journal of Special Education 12(2): 111-131. in Korean
- Arber, S. (2001). Designing samples. In: N. Gilbert (Ed.), Researching Social Life. London: Sage: 58-84.
- Archard, D. (1999). Can child abuse be defined? In: M. King. (Ed.) Moral Agendas for Children's Welfare. London: Routledge. 74-89
- Arrington, E.G., & Wilson, M.N. (2000) "A Re-examination of risk and resilience during adolescence: incorporating culture and diversity." Journal of Child and Family Studies 9(2) 221-230
- Ashworth, P. D. (1997). "The variety of qualitative research. Part two: non-positivist approaches." Nurse Education Today 17(3): 219-224.

- Aspalter, C. (2006). "The East Asian welfare model." International Journal of Social Welfare 15(4): 290-301.
- Atkinson, J. M., & Heritage, J., (Eds.) (1984). Structures of Social Action. Studies in Conversation Analysis. Cambridge: Cambridge University Press.
- Atkinson, R., & Flint, J. (2001) Accessing Hidden and Hard-to-Reach Populations: Snowball Research Strategies. Social Research Update 33 <http://sru.soc.surrey.ac.uk/SRU33.html> Access date: 21/7/2007
- Bägenholm, A., & Gillberg, C. (1991). "Psychosocial effects on siblings of children with autism and mental retardation: A population-based study." Journal of Mental Deficiency Research 35: 291-307.
- Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., & Drew, A. (2000). "A Screening instrument for autism at 18 month of age: a six-year follow-up study." Journal of the American Academy of Child and Adolescent Psychiatry 39(6): 694-702.
- Baird, G., Charman, T., Cox, A., Baron-Cohen, S., Swettenham, J., Wheelwright, S., & Drew, A. (2001). "Screening and surveillance for autism and pervasive developmental disorders." Archives of Disease in Childhood 84(6): 468-475.
- Ball, M., & Smith, G. (2001). Technologies of realism? Ethnographic uses of photography and film. In: P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.) Handbook of Ethnography. London: Sage: 302-319.
- Banks, M. (1995). Visual research methods. Social Research Update 11 <http://sru.soc.surrey.ac.uk/SRU11/SRU11.html> Access date: 20/4/2005
- Banks, M. (2001). Visual Methods in Social Research. London: Sage.
- Banks, M. (2007). Using Visual Data in Qualitative Research. London: Sage.
- Banks, P., Cogan, N., Deeley, S., Hill, M., Riddell, S., & Tisdall, K. (2001). "Seeing the invisible children and young people affected by disability." Disability & Society 16(6): 797-814.
- Baranek, G. T. (1999). "Autism during infancy: a retrospective video analysis of sensory-motor and social behaviours at 9-12 months of age." Journal of Autism and Developmental Disorders 29(3): 213-224.
- Barker, J., & Weller, S. (2003). "Never work with children?' the geography of methodological issues in research with children." Qualitative Research 3(2): 207-227.
- Barnes, C., & Mercer, G. (2003). Disability. Cambridge: The Polity Press.

- Barnes, D. B., Taylor-Brown, S., & Wiener, L. (1997). "'I Didn't Leave Y'all on Purpose': HIV-Infected mothers' videotaped legacies for their children." Qualitative Sociology 20(1): 7-32.
- Baron-Cohen, S. (2000) "Is Asperger syndrome/high-functioning autism necessarily a disability?" Development and Psychopathology, 12 (3). 489–500
- Barr, J., McLeod, S., & Daniel, G. (2008). "Siblings of children with speech impairment: cavalry on the hill." Language, Speech, and Hearing Services in Schools. 39(1): 21-32.
- Barrera, M., Fleming, C.F., & Khan, F.S. (2004). "The role of emotional social support in the psychological adjustment of siblings of children with cancer." Child: Care, Health & Development 30(2): 103-111.
- Baumann, S. L., Dyches, T.T., & Braddick, M. (2005). "Being a sibling." Nursing Science Quarterly. 18(1): 51-58.
- Bauminger, N., & Yirmiya, N. (2001). The functioning of well-being of siblings of children with autism. In: J. Burack, T. Charman, N. Yirmiya, & P.R. Zelazo (Eds.) The developmental of Autism: Perspectives from theory and research. NJ: Lawrence Erlbaum Association: 61-80.
- Baxter, C., Cummins, R.A., & Yiolitis, L. (2000). "Parental stress attributed to family members with and without disability: A longitudinal study." Journal of Intellectual & Developmental Disability 25(2): 105-118.
- Beasley, S., & Moore, M. (1996). Family lives of hearing children with deaf parents. In: M. Moore, Sixsmith, J., & Knowles (Eds.) Children's Reflections on Family Lives. K. London: Falmer Press.: 81-99.
- Becker, H. (1998). Visual Sociology: Documentary Photography, and Photojournalism: It's (Almost) All a Matter of Context. In: J. Prosser (Ed.) Image-based Research: A Sourcebook for Qualitative Researchers. London: Falmer Press: 84-96.
- Becker, S., (Ed.) (1995). Young Carers in Europe: An Exploratory Cross-National Study in Britain, France, Sweden and Germany. Loughborough: Young Carers Research Group, Loughborough University.
- Becker, S. (2000). Young carers. In: M. Davies, The Blackwell Encyclopaedia of Social Work. Oxford: Blackwell Publishers: 378.
- Becker, S. (2005) Young Carers: Evidence and Messages from UK and Australian Research. [http://www.carers-sa.asn.au/yc/pdf/Saul\\_Becker\\_au\\_paper18102005.pdf](http://www.carers-sa.asn.au/yc/pdf/Saul_Becker_au_paper18102005.pdf)  
Access date: 28/4/2008
- Becker, S. (2007). "Global perspectives on children's unpaid caregiving in the family: research and policy on 'young carers' in the UK, Australia, the USA and Sub-Saharan Africa." Global Social Policy 7(1): 23-50.

- Becker, S., Aldridge, J., & Dearden, C. (1998). Young Carers and Their Families. Oxford: Blackwell Science.
- Becker, F., & Becker, S. (2008) Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24. Woodford Green: The Princess Royal Trust for Carers.
- Beers, H. V. (2002). Children's Participation: experiences in capacity building and training. Stockholm: Save the Children.
- Benderix, Y., & Sivberg, B. (2007). "Siblings' experiences of having a brother or sister with autism and mental retardation: a case study of 14 siblings from five families." Journal of Pediatric Nursing 22(5): 410-418.
- Beresford, B. (1994). Positively Parents: caring for a severely disabled child. London, HMSO.
- Beresford, B. (1997). Personal Accounts: Involving Disabled Children in Research. London: HMSO.
- Berger, J. (1972). Ways of Seeing. London: British Broadcasting Corp/ Penguin Book.
- Berger, P. L., & Luckmann, T. (1967). The Social Construction of Reality: a treatise in the sociology of knowledge. London: Lane.
- Bernabei, P., & Camaioni, L. (2001). "Developmental profile and regression in a child with autism: a single case study." Autism 5(3): 287-297.
- Bernabei, P., Camaioni, L., & Levi, G. (1998). "An evaluation of early development in children with autism and pervasive developmental disorders from Home Movies: preliminary findings." Autism 2(3): 243-258.
- Berry, J. (2004). An Ecocultural perspective on the development of competence. In: R. Sternberg, & E. Grigorenko (Eds.) Culture and Competence: contexts of life success. Washington, DC: American Psychological Association.: 3-22.
- Berry, J. W., & Poortinga, Y.H. (2006). Cross-cultural theory and methodology. In: J. Georgas, J. W. Berry, F. J. R. van de Vijver, Ç, Kağıtçıbaşı, and Y. H. Poortinga (Eds.) Families Across Cultures: a 30-nation psychological study. Cambridge: Cambridge University Press: 51-71.
- Bertrand, J., Mars, A., Boyle, C., Bove, F., Yeargin-Allsopp, M., & Decoufle, P. (2001). "Prevalence of autism in a United States population: the brick township, New Jersey, investigation." Pediatrics 108(5): 1155-1161.
- Blacher, J., & McIntyre, L.L (2006). "Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural difference in family impact." Journal of Intellectual Disability Research 50(3): 184-198.

- Bloustien, G., & Baker, S. (2003). "On not talking to strangers: researching the micro worlds of girls through visual auto-ethnographic practices." Social Analysis 47(3): 64-79.
- Bluebond-Langner, M. (1996). In the Shadow of Illness: parents and siblings of the chronically ill child. NJ: Princeton University Press.
- Bogdan, R., & Taylor, S.T. (1975). Introduction to Qualitative Research Methods: a phenomenological approach to the social sciences. NY: Wiley.
- Bolger, N., Davis, A., & Rafaeli, E. (2003). "Diary Methods: capturing life as it is lived." Annual Review of Psychology 54: 579-616.
- Brannen, J. (2002). "The Use of video in research dissemination: children as experts on their own family lives." International Journal of Social Research Methodology 5(2): 173-180.
- Breslau, N. (1982). "Siblings of disabled children: birth order and age-spacing effects." Journal of Abnormal Child Psychology 10(1): 85-96.
- Breslau, N. (1983). "The Psychological study of chronically ill and disabled children: are healthy siblings appropriate controls?" Journal of Abnormal Child Psychology 11(379-391).
- Briggs, J., & Sharp, J. (2004). "Indigenous knowledges and development: a postcolonial caution." Third World Quarterly 25(4): 661-676.
- Brislin, R. W. (1970). "Back-translation for cross-cultural research." Journal of Cross-Cultural Psychology 1(3): 185-216.
- Bristol-Power, M. M., & Spinella, G. (1999). "Research on screening and diagnosis in autism: a work in progress." Journal of Autism & Developmental Disorders 29(6): 435-438.
- Brody, G. H. (1998). "Sibling relationship quality: its causes and consequences." Annual Review of Psychology 49: 1-24.
- Brody, G. H., & Stoneman, Z. (1996). A risk-amelioration model of sibling relationships: conceptual underpinnings and preliminary findings. In: G. H. Brody (Ed.) Sibling Relationships: their causes and consequences. Norwood, NJ, Ablex: 231-247.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). "Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services." Autism 8(4): 409-423.
- Bronfenbrenner, U. (1979). The Ecology of Human Development: experiments by nature and design. Cambridge, MA: Harvard University Press.
- Brooks, R. A. (2000). Official madness: a cross-cultural study of involuntary civil confinement based on 'mental illness'. IN: J. Hubert (Ed.) Madness, Disability and

Social Exclusion: The Archaeology and Anthropology of Difference (One World Archaeology). London: Routledge: 9-28.

Broszormenyi-Nagy, I., & Spark, G. M. (1973). Invisible loyalties: reciprocity in intergenerational family therapy. Hagerstown, MD: Harper & Row.

Brown, J., & Brown, J. (2006). Child, Japan, Korea Culture and Customs. North Charleston, South Carolina: BookSurge LLC.

Brown, S. E. (2002). "What Is Disability Culture?" Disability Studies Quarterly 22(2): 34-50.

Browne, K. (2005). "Snowball sampling: using social networks to research non-heterosexual women." International Journal of Social Research Methodology 8(1): 47-60.

Bryman, A. (2001). Social Research Methods. London: Oxford University Press.

Burke, P. (2004). Brother and Sisters of disabled children. London: Jessica Kingsley Publishers.

Burke, P. (2007). Disadvantage and stigma: a theoretical framework for associated conditions. [In: P. Burke, & J. Parker (Eds.) Social Work and Disadvantage: addressing the roots of stigma through association. London: Jessica Kingsley Publishers: 11-26.

Burke, P., & Montgomery, S. (2000). "Siblings of children with disabilities: a pilot study." Journal of Learning Disabilities 4(3): 227-236.

Burke, P., & Montgomery, S. (2003). Finding a Voice. Birmingham: Venture press.

Burke, P., & Parker, J., (Eds.) (2007). Social Work and Disadvantage: addressing the roots of stigma through association. London: Jessica Kingsley Publishers.

Burkitt, E., Barrett, M. & Davis, A. (2003). "Children's colour choices for completing drawing of affectively characterised topics." Journal of Child Psychology and Psychiatry 44(3): 445-455.

Burr, R. (2004). Children's rights: international policy and lived practice. In: M. J. Kehily (Ed.) A Introduction of Childhood Studies. Berkshire, Maidenhead: Open University Press: 145-159.

Burnsall, S. (2003). Regaining Equilibrium: Understanding the Process of Sibling Adjustment to Pediatric Acquired Brain Injury. Griffith University. PhD Thesis.

Butler, A. H., & Astbury, G. (2005). "The caring child: an evaluative case study of the Cornwall Young Carers Project." Children & Society 19(4): 292-303.

Butt, J., Moriarty, J., Brockmann, M., Sin, C. H., & Fisher, M. (2003). Quality of life and social support among older people from different ethnic group: Research Findings from the Growing Older Programme 2003, ESRC. Research No. L480254037  
<http://www.shef.ac.uk/uni/projects/gop/GOFindings23.pdf> Access date: 5/5/2007

Byrne, B. (2004) Qualitative interviewing In: C. Seale (Ed.) Researching Society and Culture 2<sup>nd</sup> London: Sage. 179-192

Byun, Y. C. (2002). "Evaluation of policy for disabled persons and future policy directions." Policy Forum 74(December). in Korean

Byun, Y. C., Kim, S.H., Yun, S.Y., & Im, S.E. (2005). A Study on Status and Improving Implications of Welfare Facilities for the Disabled in Korea. Korea, Seoul: KIHASA. in Korean

Byun, Y. C., Kim, S.H., Yun, S.Y., Bea, H.O., Park, S.M., & Choi, M.Y. (2004). A Study on Systematic Income Security for the Disabled in Korea. Korea, Seoul: KIHASA. in Korean

Byun, Y. C., Kim, S.H., Yun, S.Y., Choi, M.Y., Gye, H.B., Kwon, S.J., & Lee, S.W. (2006a). 2005 the National Survey on People with Disabilities. Korea Seoul: Ministry of Health and Welfare. in Korean

Byun, Y. C., Kim, S.H., Yun, S.Y., Kwon, S.J., Cho, H.S., Cho, S.R., Kang, J.G., & Choi, S.H. (2006b). A Study of the Characteristics of the Persons with Disabilities Based on the Life Cycle Perspectives. Korea, Seoul: KIHASA. in Korean

Byun, Y. C., Seo, D.W., Lee, S.W., Kim, S.H., Hwang, J.H., Kwon S.J., & Gye, H.B. (2001). 2000 the National Survey on Disabled People (Policy Paper 2001-03). Korea, Seoul: Ministry of Health and Welfare, KIHASA. in Korean

Callahan, W. A. (1999). "Negotiating cultural boundaries: Confucianism and trans/national Identity in Korea." Cultural Values 3(3): 329-364.

Cameron, C., Ungar, M., & Liebenberg, L. (2007). "Cultural understandings of resilience: roots for wings in the development of affective resources for resilience." Child and Adolescent Psychiatric Clinics of North America 16(2) 285-301.

Carers UK. (2005). "Policy briefing: children and young people who have caring responsibilities." Retrieved 10. May., 2007,  
<http://www.carersuk.org/Policyandpractice/PolicyResources/Policybriefings/youngcarers.pdf>.

Carol, C., & Mikelle, R. (1997). "Brothers and Sisters: We're Special, too!" Disability Solutions 2(3): 1-7.

Casarett, D., & Karlawish, J. (2000) "Are special ethical guidelines needed for palliative care research?" Journal of Pain and Symptom Management, 20(2) 130-139.



- Cason, T. S. (2007). The Rhetoric of Disablement and Repair in the Testament of Job. The Florida State University. PhD Thesis.
- Cate, I. M. P. T., & Loots, G.M.P. (2000). "Experiences of siblings of children with physical disabilities: an empirical investigation." Disability & Rehabilitation 22(9): 399-408.
- Chakrabarti, S., & Fombonne, E. (2001). "Pervasive developmental disorders in pre-school children." The Journal of American Medical Association 285(24): 3093-3099.
- Chalfen, R. (1987). Snapshot Versions of Life. Bowling Green, Ohio: Bowling Green State University Press.
- Chamorro, R. (2004). "Mentoring the parentified child: the professional development of the Latina(O) psychologist." Journal of Hispanic Higher Education 3(1): 64-72.
- Chang, K. S. (2003). "The State and families in South Korea's compressed fertility transition: a time for policy reversal?" Journal of Population and Social Security: Population Study 1(1 Supplement to Volume1): 596-610.
- Chang, J., Rhee, S., & Weaver, D. (2006) "Characteristics of child abuse inimmigrant Korean families and correlates of placement decisions." Child Abuse & Neglect 30(8) 881-891
- Charman, T., & Baird, G. (2002). "Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children." Journal of Child Psychology & Psychiatry 43(3): 289-305.
- Che, H. C., Kim, D.J., Park, E.J., Yoo.D.Y., & Kim, C.G. (2007). [Exploration] over half of parents having children with mentally disabilities said 'I wish leave Korea'. SE-GYE-II-Bo. in Korean
- Chee, Y. K., & Levkoff, S.E. (2001). "Culture and dementia: Accounts by family caregivers and health professionals for dementia-affected elders in South Korea." Journal of Cross-Cultural Gerontology 16(2): 111-125.
- Chiarenza, C., & Luxenberg, A. (2004). "Photography and painting: the evolution of modern picture making in France ca. 1860-1880." Exposure 37(1): 3-16.
- Cho, S. H., & Kim, H. R. (2006). "Family and paid caregivers of hospitalized patients in Korea." Journal of Clinical Nursing 15(8): 946-953.
- Cho, S. J., Singer, G.H.S., & Brenner, B. (M). (2003). "A Comparison of adaptation to childhood disability in Korean immigrant and Korean Mothers." Focus on Autism and Other Developmental Disabilities 18(1): 9-19.
- Cho, Y. T. (2002). "Characteristics of Mentally Retarded children with and without Cheong." Journal of Special Education 9(2): 169-185. in Korean

- Cho, Y. T. (2004). "Cultural issues of diagnosis and evaluation on abnormal behaviors of the children with developmental disabilities." The Journal of the Korean Association on Developmental Disabilities 8(2): 85-101. in Korean
- Choe, Y. H. (2001). Intercultural conflict patterns and intercultural training implications for Koreans. the 16th Biennial World Communication Association Conference, The University of Cantabria, Spain.
- Choi, G. H., & Lam, C.S. (2001). "Korean students' differential attitudes toward people with disabilities: an acculturation perspective." International Journal of Rehabilitation Research 24(1): 79-81.
- Choi, I. J., & Choi, S.C. (2002). "The Effects of Korean cultural psychological characteristics on coping styles, stress, and life satisfaction: centering around Cheong and We-ness." The Korean Journal of Counseling and Psychotherapy 14(1): 55-71. in Korean.
- Choi, J. S., & Choi, J.K. (2006). "The Effectiveness of poverty reduction and the target efficiency of social security transfers in South Korea, 1999-2003." International Journal of Social Welfare Online EarlyView Article.
- Choi, M. J. (2001). A Study on the Stress and Coping Skills of Siblings of Children with Autistic Disorder. Dan-Kook University. MA Dissertation. in Korean
- Choi, M. S. (2003). Family Support and Participation for Disabled children. Korea, Seoul: Hakjisa. in Korean
- Choi, S. C. (2000). The Psychology of Korean. Seoul: Chung-Ang University Press. in Korean
- Choi, S. C., & Choi, S. H. (1990). "We-ness: A Korean discourse of collectivism." Retrieved 12 March, 2005, from <http://cau.ac.kr/~choi/non.htm>. in Korean
- Choi, S. C., & Lee, J.J. (1999). "The Psychological interior and social-cultural functions of Korean Cheong." Korean Journal of Social and Personality Psychology 13(1): 219-234. in Korean
- Choi, S. C., & Lee, S.J. (2002). "Two-component model of Chemyon-oriented behaviors in Korea: constructive and defensive Chemyon." Journal of Cross-Cultural Psychology 33(3): 332-345.
- Choi, S. J. (2004). "Development of a new concept of filial piety in modern Korean society." Geriatrics and Gerontology International 4(S1): s72-s73.
- Choi, S. K., & Lee, S.J. (2005). "Research on understanding and recognition of the elementary school students about the terminology related to the disabilities." Journal of Special Education & Rehabilitation Science 44(1): 127-154. in Korean

Christensen, P., & Prout, A. (2002). "Working with ethical symmetry in social research with children." Childhood 9(4): 477-497.

Christensen, P., & Prout, A., (Ed.) (2000). Research with Children: perspectives and practices. London: Falmer Press.

Christensen, P. H. (2004). "Children's participation in ethnographic research: issues of power and representation." Children & Society 18(2): 165-176.

Chun, H. I. (1997). A Study of Non-handicapped Sibling Support Program Effect in Self-Concept and Behaviour toward Siblings with Disabilities. Ewha University. MA Dissertation. in Korean

Chun, H. I. (2001). "Support programme for siblings of disabled children." Journal of Special Education Practices 8(5): 74-79. in Korean

Chun, H. I. (2003). The Effects of Support Programme for Siblings of Disabled Children: focus on the effects of communication between disabled students and non-disabled students. 7th Ehwa Special Education Conference, Seoul. in Korean

Chun, H. I. (2006). Family Support for Families with the Disabled. 22th Forum of Korean Parents of People with Disabilities, Seoul. in Korean

Chun, H. I., & Park, E.H. (1998). "A Study of sibling support program for siblings of children with disabilities." Ewha Journal of Educational Research 27: 129-144. in Korean

Chung, B. H. (2001). "Changes in Korean family structure and the conflicts of ideology and practice in early socialization." Korea Journal 40(4): 123-143.

Chung, E. S. (1993). "A Study on self-concept and frustration of siblings of mentally retarded children." Journal of Nurses Academic Society 23(1): 90-106. in Korean

Chung, Y. S. (2005a). "Level of need and poverty of families with disability children." Journal of Special Education & Rehabilitation Science 44(4): 101-125. in Korean

Chung, Y. S. (2005b). "Measuring poverty and minimum cost of living: focus on children with developmental disability and the cost of educational therapy." Journal of Emotional & Behavioral Disorders 21(1): 69-91. in Korean

Chung, Y. S., & Han, S.I. (2005). A Study of measurement for poverty & minimum living cost: centred families of disabled children. 2005 Korea Academy of Social Welfare Autumn conference, in Korean

Chung, Y. S., & Lee, S.B. (2001). "Pattern dimensions for children with developmental disabilities and family welfare model." Korean Journal of Special Education 36(3): 1-23. in Korean

Chung, Y. S., Lee, S.B., & Chung, B.I. (2003). Children with Developmental Disability and Family Welfare. Seoul: Hyun-Hak-Sa. in Korean

- Chung, Y. S., Lee, S.B., Jang, B.I., Hong, K. (2001). Welfare policy and type of poverty for the families of children with disabilities. 2001 Korean Academy of Social Work Autumn Conference. in Korean
- Cicirelli, V. G. (1994). "Sibling relationships in cross-cultural perspective." Journal of Marriage and the Family 56(1): 7-20.
- Cicirelli, V. G. (1995). Sibling Relationships Across the Lifespan. NY: Plenum Press.
- Clapton, J., & Fitzgerald, J. (1997). "The History of Disability: A History of 'Otherness'." New Renaissance magazine 7(1). <http://www.ru.org/artother.html> Access date: 27/3/2008
- Collier, J. J., & Collier, M. (1986). Visual Anthropology: photography as a research method. Albuquerque: University of New Mexico Press.
- Colver, A. (2005). "A Shared framework and language for childhood disability." Developmental Medicine & Child Neurology 47(11): 780-784.
- Connors, C., & Stalker, K. (2004). "Children's perceptions of their disabled siblings: she's different but it's normal for us." Children & Society 18(3): 218-230.
- Connors, C., & Stalker, K. (2003). The Views and Experience of Disabled Children and Their Siblings: a positive outlook. London: Jessica Kingsley Press.
- Connors, C., Carpenter, J., Imam, U., Griffin, M., & Eyre, J. (2004). Meeting the Needs of Severely Disabled Pakistani and Bangladeshi Children and their Families. Durham: University of Durham Centre for Applied Social Studies.
- Conyers, L. M. (2003). "Disability culture: a cultural model of disability." Rehabilitation Education 17(3): 139-154.
- Cook, S., & Kwon, H.J. (2007). "Social protection in East Asia." Global Social Policy 7(2): 223-229.
- Cooper, C. (1999). Multiple selves, multiple worlds: cultural perspectives on individuality and connectedness in adolescent development. In: A. Masten, Cultural Processes in Child Development. Mahwah, NJ: Lawrence Erlbaum Associates: 25-57.
- Cornwall, A., & Nyamu-Musembi, C. (2004). "Putting the 'rights-based approach' to development into perspective." Third World Quarterly. 25(8): 1415-1437.
- Corsaro, W. (1997). The Sociology of Childhood. London: Pine Forge Press.
- Cox, A. H., Marshall, E.S., Mandleco, B., & Olsen, S.F. (2003). "Coping responses to daily life stressors of children who have a siblings with a disability." Journal of Family Nursing 9(4): 397-413.

- Crang, M. (1997). "Picturing practices: research through the tourist gaze." Progress in Human Geography 21(3): 359-373.
- Crang, M., & Cook, I. (2007). Doing Ethnographies. London: Sage.
- Crano, W.D., & Brewer, M.B. (2002) Principles and Methods of Social Research. 2<sup>nd</sup> ed. Mahwah, New Jersey: Lawrence Erlbaum Associates
- Cree, V. E. (2003). "Worries and problems of young carers: issues for mental health." Child and Family Social Work 8(4): 301-309.
- Cree, V. E., Kay, H., & Tisdall, K. (2002). "Research with children: sharing the dilemmas." Child & Family Social Work 7(1): 45-56.
- Croissant, A. (2004). "Changing welfare regimes in East and South-East Asia: crisis, change and challenge." Social Policy and Administration 38(5): 504-524.
- Crotty, M. (1998). The Foundations of Social Research: meaning and perspective in the research process. London, Sage.
- Crow, L. (1996). Including all of our lives: renewing the social model of disability. In: C. Barnes, & G. Mercer (Eds.) Exploring the Divide. Leeds: The Disability Press: 55-72.
- Cunningham, C. C. (1996). "Families of children with Down syndrome." Down Syndrome Research and Practice 4(3): 87-95.
- Cuskelly, M. (1999). "Adjustment of siblings of children with a disability: Methodological issues." International Journal for the Advancement of Counselling 21(2): 111-124.
- Cuskelly, M., & Dadds, M. (1992). "Behavioural Problems in Children with Down's Syndrome and their Siblings." Journal of Child Psychology and Psychiatry 33(4): 749-761.
- Cuskelly, M., & Gunn, P. (1993). "Maternal reports of behavior of siblings of children with Down syndrome." American Journal on Mental Retardation 97(5): 521-529.
- Cuskelly, M., & Gunn, P. (2003). "Sibling relationships of children with Down syndrome: perspectives of mothers, fathers, and siblings." American Journal on Mental Retardation 108(4): 234-244.
- Cuskelly, M., Chant, D., & Hayes, A. (1998). "Behaviour Problems in the Siblings of Children With Down Syndrome: associations with family responsibilities and parental stress." International Journal of Disability, Development and Education, 45(3): 295-311.
- Cutcliffe, J. R., & McKenna, H.P. (1999). "Establishing the credibility of qualitative research findings: the plot thickens." Journal of Advanced Nursing 30(2): 374-380.

- David, M., Edwards, R., & Aldred, P. (2001) "Children and school-based research: 'informed consent' or 'educated consent'?" British Educational Research Journal 27(3) 347-365
- D'Arcy, F., Flynn, J., McCarthy, Y., O'Connor, C., & Tierney, E. (2005). "Sibshops: an evaluation of an interagency model." Journal of Intellectual Disabilities 9(1): 43-57.
- Dalal, A. K., & Pande, N. (1999). "Cultural beliefs and family care of the children with disability." Psychology & Developing Societies 11(1): 55-75.
- Daley, T. C. (2002). "The Need for cross-cultural research on the pervasive developmental disorders." Transcultural Psychiatry 39(4): 531-550.
- Dallas, E., Stevenson, J., & McGurk, H. (1993). "Cerebral-palsied children's interactions with siblings- I. influence of severity of disability, age and birth order." Journal of Child Psychology and Psychiatry 34(5): 621-647.
- Damiani, V. B. (1999). "Responsibility and adjustment in siblings of children with disabilities: update and review." Families in Society: The Journal of Contemporary Social Services 80(1): 34-40.
- Daniels, D. (2008) Exploring ethical issues when using a visual tools in educational research. In: P. Liamputtong (Ed.) Doing Cross-Cultural Research: ethical and methodological perspectives. London: Springer. 119-136
- Daniels, D., & Plomin, R (1985). "Differential Experience of Siblings in the Same Family." Developmental Psychology 21(5): 747-760.
- Daniels, D., Moos, R.H., Billings, A.G., & Miller III, J.J. (1987). "Psychosocial Risk and Resistance Factors Among Children with Chronic Illness, Healthy Siblings, and Healthy Controls." Journal of Abnormal Child Psychology 15(2): 295-308.
- Dant, T. (2004). Recording the habitus. In: C. J. Pole (Ed.). Seeing is Believing? approaches to visual research. Oxford: Elsevier. 41-60.
- Davis, C. S., & Salkin, K.A. (2005). "Sisters and Friends: Dialogue and Multivocality in a Relational Model of Sibling Disability." Journal of Contemporary Ethnography 34(2): 206-234.
- Davis, L. J. (1995). Enforcing Normalcy: disability, deafness, and the body. NY: Verso.
- Deacon, S. A. (2000) Creativity within qualitative research on families: new ideas for old methods. The Qualitative Report 4(3-4), <http://www.nova.edu/ssss/QR/QR4-3/deacon.html> Access date: 23/2/2005
- Dearden, C., & Becker, S. (1995). Young Carers: The Facts. Sutton: Reed Business Publishing.

- Dearden, C., & Becker, S. (1996). Crossroads: getting it right for young carers. Loughborough: Department of Social Science, Loughborough University, Young Carers Research Group.
- Dearden, C., & Becker, S. (1997). Children in care, Children who care: parental illness and disability and the child care system. Loughborough: Young Carers Research Group, Loughborough University.
- Dearden, C., & Becker, S. (1998). Young Carers in the United Kingdom: a profile. London: Carers National Association.
- Dearden, C., & Becker, S. (2000). Growing Up Caring: vulnerability and transition to adulthood: young carers' experiences. Leicester: National Youth Agency in association with Joseph Rowntree Foundation.
- Dearden, C., & Becker, S. (2001). Young carers: needs, rights and assessment. In: J. Howarth (Ed.) The Child's World: assessing children in need. London: Jessica Kingsley: 221-233.
- Dearden, C., & Becker, S. (2002). Young Carers and Education. London: Carers UK.
- Dearden, C., & Becker, S. (2004). Young Carers in the UK: The 2004 Report. London: Carers UK.
- Deater-Deckard, K., Pike, A., Petrill, S.A., Cutting, A. L., Hughes, C., & O'Connor, T. G. (2001). "Nonshared environmental processes in socialemotional development: an observational study of identical twin differences in the preschool period." Developmental Science 4(2): f1-f6.
- Dempsey, I., & Foreman, P. (2001). "A Review of educational approaches for individuals with autism." International Journal of Disability, Development and Education 48(1): 103-116.
- De Boo, G.M., & Wicherts, J.M. (2009) "Assessing Cognitive and Behavioral Coping Strategies in Children." Cognitive Therapy and Research. 33(1) 1-20.
- DeMyer, M. K. (1979). Parents and Children in Autism. NY: Wiley.
- Denzin, N. (1997). Interpretive Ethnography: ethnographic practices for the 21st century. Thousand Oaks, CA: Sage.
- Department of Health. (1989). "The Children Act 1989." <http://www.hmso.gov.uk/acts/acts1989>. Access date: 2/3/2005
- Department of Health (1990) The National Health Service and Community Care Act 1990. London: Department of Health.
- Department of Health (1991). The Children Act 1989 Guidance and Regulations. London: HMSO.

Department of Health (1995). The Carer (Recognition and Services) Act. London: Department of Health.

Department of Health (2000a). Assessing Children in Need and their families: Practice guidance. London: The Stationary Office.

Department of Health (2000b). The Framework for the Assessment of Children in Need and their Families. London: The Stationary Office.

Devlieger, P., Rusch, F., & Pfeiffer, D. (2003). Rethinking disability as same and different! Towards a cultural model of disability. In: P. Devlieger, F. Rusch, & D. Pfeiffer (Eds.) Rethinking Disability: the emergence of new definitions, concepts and communities. Antwerpen: Garant: 9-16.

Devlieger, P. J. (2005). Generating a Cultural Model of Disability. the 19th Congress of the European Federation of Associations of Teachers of the Deaf (FEAPDA), Geneva.

Devlieger, P. J., Albrecht, G.L., & Hertz, M. (2007). "The Production of disability culture among young African-American men." Social Science & Medicine 64(9): 1948-1959.

Dew, A., Llewellyn, G., & Baladin, S. (2004). "Post-parental care: a new generation of sibling-carers." Journal of Intellectual & Developmental Disability 29(2): 176-179.

Dicks, B., Mason, B., Coffey, A., & Atkinson, P. (2005). Qualitative Research and Hypermedia: ethnography for the digital age. London: Sage.

Dicks, B., Soyinka, B., & Coffey, A. (2006). "Multimodal ethnography." Qualitative Research. 6(1): 77-96.

Diem-Wille, G. (2001). A Therapeutic perspective: the use of drawings in child psychoanalysis and social science. In: T. Van Leeuwen, & C. Jewitt (Eds.) Handbook of Visual Analysis. London: Sage: 119-133.

Disabled Person (Services, Consultation and Representation) Act 1986, HMSO.

Do, M. H. (2004). "A Study on child welfare policies and related laws in Korea." Korean Journal of Family Welfare 9(2): 35-50. in Korean

Dodd, L. W. (2004). "Supporting the Siblings of young children with disabilities." British Journal of Special Education 31(1): 41-49.

Donnelly, P. L. (2001). "Korean American family experiences of caregiving for their mentally ill adult children: an interpretive inquiry." Journal of Transcultural Nursing 12(4): 292-301.



- Dorna, L. D., Susmanb, E.J., & Fletcherc, J.C. (1995). "Informed consent in children and adolescents: Age, maturation and psychological state." Journal of Adolescent Health 16(3): 185-190.
- Dowling, M., & Dolan, L. (2001). "Families with children with disabilities: inequalities and the social model." Disability & Society 16(1): 21-35.
- Doy, G. (2005). Picturing the Self: changing views of the subject in visual culture. London: I.B.Tauris.
- Doyle, B. T., & Iland, E.D. (2004). Autism Spectrum Disorders From A to Z: assessment, diagnosis & more! Texas, Arlington: Future Horizons.
- DuFon, M. A. (2002). "Video recording in ethnographic SLA research: some issues of validity in data collection." Language, Learning & Technology 6(1): 40-59.
- Dunn, J. (2000). "State of art: siblings." The Psychologist 13(5): 244-248.
- Dunn, J. (2004). Sibling relationships. In: P.K. Smith., & C.H. Hart (Eds.) Blackwell Handbook of Childhood Social Development. Oxford: Blackwell: 223-237.
- Dunn, J. (2005). "Commentary: siblings in their families." Journal of Family Psychology 19(4): 654-657.
- Dunn, J., & Kendrick. C. (1982). Siblings: love, envy & understanding. London: Grant McIntyre.
- Dunn, J., & Plomin, R. (1990). Separate Lives: why siblings are so different. New York: Basic Books.
- Dunn, J., Deater-Deckard, K., Pickering, K., Golding, J., & the ALSPAC study team (1999). "Siblings, parents and partners: family relationships within a longitudinal community study." Journal of Child Psychology and Psychiatry 40(7): 1025-1037.
- Dyches, T. T., Wilder, L.K., Sudweeks,R.R., Obiakor, F.E., & Algozzine, B. (2004). "Multicultural Issues in Autism." Journal of Autism and Developmental Disorders 34(2): 211-222.
- Dykens, E. M. (2005). "Happiness, well-being, and character strengths: outcomes for families and siblings of persons with Mental Retardation." Mental Retardation 43(5): 360-364.
- Dyson, L. L. (1989). "Adjustment of siblings of handicapped children: a comparison." Journal of Pediatric Psychology 14(2): 215-229.
- Dyson, L. L. (1996). "The experiences of families of children with learning disabilities: parental Stress, family functioning, and sibling self-concept." Journal of Learning Disabilities 29(3): 280-286.

- Dyson, L. L. (1997). "Fathers and mothers of school-age children with developmental disabilities: parental stress, family functioning and social support." American Journal on Mental Retardation 102(3): 267-279.
- Dyson, L. L. (1998). "A Support program for siblings of children with disabilities: what sibling learn and what they like." Psychology in the Schools, 35(1): 57-65.
- Dyson, L. L. (1999). "The psychosocial functioning of school-age children who have siblings with developmental disabilities: change and stability over time." Journal of Applied Developmental Psychology 20(2): 253-271.
- Dyson, L. L. (2003). "Children with learning disabilities within the family context: a comparison with siblings in global self-concept, academic self-perception, and social competence." Learning Disabilities Research & Practice 18(1): 1-9.
- Earl, T. R. (2005). How Important is Race and Ethnicity? Examining Caregiving Practices of Siblings Caring for a Brother or Sister Diagnosed with a Severe Mental Illness. The University of Texas. PhD Thesis.
- Earley, L., & Cushway, D. (2002). "The parentified child." Clinical Child Psychology and Psychiatry 7(2): 163-178.
- Earley, L., Cushway, D., & Cassidy, T. (2007). "Children's perceptions and experiences of care giving: a focus group study." Counseling Psychology Quarterly 20(1): 69-80.
- Early, L., Cushway, D., & Cassidy, T. (2006). "Perceived stress in young carers: development of a measure." Journal of Child and Family Studies 15(2): 169-180.
- Eaves, L. C., Wingert, H., & Ho, H.H. (2006). "Screening for autism: agreement with diagnosis." Autism 10(3): 229-242.
- Eco, U. (2003). Mouse or Rat? translation as negotiation. London: Phoenix.
- Eder, D., & Corsaro, W. (1999). "Ethnographic studies of children and youth." Journal of Contemporary Ethnography 28(5): 520-531.
- Edwards, R & Alldred, P (1999) "Children and young people's views of social research: the case of research on home-school relations" Childhood, 6(2) 261-281
- Edwards, R., Hadfield, L., Lucey, H., & Mauthner, M. (2006). Sibling Identity and Relationships: sisters and brothers. Abingdon: Routledge.
- Edwards, R., Mauthner, M., & Hadfield, L. (2005). "Children's sibling relationships and gendered practices: talk, activity and dealing with change." Gender and Education 17(5): 499-513.
- Ehlers, S., & Gillberg, C. (1993). "The Epidemiology of Asperger syndrome. A total population study." Journal of Child Psychology and Psychiatry. 34(6): 1327-1350.

Eisenberg, L., Baker, B.L., & Blacher, J. (1998). "Siblings of children with mental retardation living at home or in residential placement." The Journal of Child Psychology & Psychiatry 39(3): 355-363.

Eley, S. (2004). "'If they don't recognize it, you've got to deal with it yourself': gender, young caring and educational support." Gender & Education 16(1): 65-75.

Emmison, M., & Smith, P. (2000). Researching the Visual: images, objects, contexts and interactions in social and cultural inquiry. London: Sage.

Emond, R. (2005). Ethnographic research methods with children and young people. In: S. Green, & D. Hogan (Eds.) Researching Children's Experience: approaches and methods. London: Sage: 123-140.

Engwall, P., & MacPherson, E. (2003). "An Evaluation of the NAS EarlyBird programme." Good Autism Practice 4(1): 13-19.

Eom, J. W. (2004). The Influence of communication between parents and non-disabled siblings on the stress of non-disabled siblings: focused on schooling aged siblings. Department of Social Work. Seoul, Yon-Sei University. in Korean

Erickson, J. G., Devlieger, P.J., & Sung, J.M. (1999). "Korean-American female perspectives on disability." American Journal of Speech-Language Pathology 8(2): 99-108.

Evans, J., Jones, J. & Mansell, I. (2001). "Supporting siblings: evaluation of support groups for brothers and sisters of children with learning disabilities and challenging behaviour." Journal of Learning Disabilities 5(1): 69-78.

Farber, B.A. (2006) Self-Disclosure in Psychotherapy. NY: Gilford Press.

Farver, J. A. M., Kim, Y.K., & Lee-Shin, Y.L. (2000). "Within cultural differences: examining individual differences in Korean American and European American preschoolers' social pretend play." Journal of Cross-Cultural Psychology 31(5): 583-602.

Fasoli, L. (2003). "Reading photographs of young children: looking at practices." Contemporary Issues in Early Childhood, 4(1): 32-47.

Faugier, J., & Sargeant, M. (1997). "Sampling hard to reach populations." Journal of Advanced Nursing 26 (4): 790-797.

Ferguson, L. R. (1978). "The competence and freedom of children to make choices regarding participation in research: a statement" Journal of Social Issues 34, 114-121.

Ferrari, M. (1984). "Chronic illness: psychosocial effects on siblings-I, chronically ill boys." Journal of Child Psychology and Psychiatry 25(3): 459-476.

Fine, G. A., & Sandstrom, K. L. (1988). Knowing Children: participant observation with minors. London, Sage.

- Fine, M., & Asch, A. (2000). Disability beyond Stigma: Social Interaction, Discrimination and Activism. In: M. Adams, W.J. Blumenfeld, R. Castañeda, H.W. Hackman, M.L. Peters, & X. Zuniga (Eds.) Readings for Diversity and Social Justice: An Anthology on Racism, Sexism, Anti-semitism, Heterosexism, Classism and Ableism. London: Routledge: 330-339.
- Fisher, C. (2003) "Goodness-of-fit ethic for informed consent to research involving adults with mental retardation and developmental disabilities." Mental Retardation and Developmental Disabilities Research Reviews 9(1). 27-31.
- Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). "A Longitudinal study of siblings of children with chronic disabilities." Canadian Journal of Psychiatry 45(4): 369-375.
- Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T., & Szatmari, P. (1996). "Risk and protective factors affecting the adjustment of siblings of children with chronic disabilities." Journal of the American Academy of Child and Adolescent Psychiatry 35(11): 1532-1541.
- Fitness, J., & Duffield, J. (2004). Emotion and communication in families. In: A. L. Vangelisti (Ed.) Handbook of Family Communication. Mahwah, NJ: Lawrence Erlbaum Associates: 473-494.
- Flekkøy, M. G., & Kaufman, M.H. (1997). The Participation Rights of the Child: rights and responsibilities in family and society. London: Jessica Kingsley Publishers.
- Floyd, F. J., & Gallagher, E.M. (1997). "Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems." Family Relations 46(4): 359-371.
- Fombonne, E. (2003). "The Prevalence of Autism." The Journal of the American Medical Association 289(1): 87-89.
- Foster, C., Eiser, C., Oades, P., Sheldon, C., Tripp, J., Goldman, P., Rice, S., & Trott, J. (2001). "Treatment demands and differential treatment of patients with cystic fibrosis and their siblings: patient, parent and sibling accounts." Child: Care, Health and Development 27(4): 349-364.
- Foucault, M. (1988). Politics, Philosophy, Culture. In: L. D. Kritzman (Ed.) Politics, Philosophy, Culture: interviews and other writings 1977-1984. NY: Routledge: 255-267.
- Foucault, M. (1997). For an ethics of discomfort. In: S. Lotringer (Ed.). The Politics of Truth: Michel Foucault. NY: Semiotext(E): 135-146.
- Foucault, M. (2002). The Archaeology of Knowledge. London: Routledge.
- Frank, J. (1995). Couldn't Care More: a study of Young Carers and their Needs. London: The Children's Society.

- Freeman, M. (2000). "The Future of children's right." Children & Society 14(4): 277-293.
- Freeman, B. J., Cronin, P., & Candela, P. (2002). "Asperger syndrome or autistic disorder? the diagnostic dilemma." Focus on Autism and Other Developmental Disabilities 17(3): 145-151.
- Frith, U. (2003). Autism: explaining the enigma. Oxford: Blackwell Publishing.
- Fulgini, A. J., & Zhang, W. (2004). "Attitudes toward family obligation among adolescents in contemporary urban and rural China." Child Development 74(1): 180-192.
- Fulgini, A. J., Tseng, V., & Lam, M. (1999). "Attitudes toward Family Obligations among American Adolescents with Asian, Latin American, and European Background." Child Development 70(4): 1030-1044.
- Fussell, J. J., Macias, M.M., & Saylor, C.F. (2005). "Social skills and behavior problems in children with disabilities with and without siblings." Child Psychiatry & Human Development 36(2): 227-241.
- Gabhainn, S. N., & Sixsmith, J. (2005). "Children photographing well-being: facilitating participation in research." Children & Society 20(4): 249-259.
- Gallo, A. M., Angst D., Knafl, K.A., Hadley, E., & Smith, C. (2005). "Parents sharing information with their children about genetic conditions." Journal of Pediatric Health Care 19(5): 267-275.
- Gamble, W. C., & McHale, S.M. (1989). "Coping with stress in sibling relationships: a comparison of children with disabled and nondisabled siblings." Journal of Applied Developmental Psychology 10(3): 353-373.
- Gardner, E. (1998). "Siblings of chronically ill children: towards an understanding of process." Clinical Child Psychology and Psychiatry 3(2): 213-227.
- Gath, A. (1974). "Sibling reactions to mental handicap: a comparison of the brothers and sisters of Mongol children." Journal of Child Psychology and Psychiatry, 15(3): 187-198.
- Gauntlett, D. (2005). "Using creative visual research methods to understand media audiences." [www.medienpaed.com/04-1/gauntlett04-1.pdf](http://www.medienpaed.com/04-1/gauntlett04-1.pdf)
- Geertz, C. (1993). Thick description: toward an interpretive theory of culture. In: C. Geertz (Ed.) The Interpretation of Cultures: selected essays. London: Fontana: 3-32.
- Georgas, J., van de Vijver, F.J. R., & Berry, J.W. (2004). "The Ecocultural framework, ecosocial indices, and psychological variables in cross-cultural research." Journal of Cross-Cultural Psychology 35(1): 74-96.

- Giallo, R., & Gavidia-Payne, S. (2006). "Child, parent and family factors as predictors of adjustment for siblings of children with a disability." Journal of Intellectual Disability Research 50(12): 937-948.
- Giles, H., Noels, K. A., Williams, A., Ota, H., Lim, T-S., Ng, S.H., Ryan, E., & Somera, L. (2003). "Intergenerational communication across cultures: young people's perceptions of conversations with family elders, non-family elders and same-age peers." Journal of Cross-Cultural Gerontology 18(1): 1-32.
- Gillham, J. E., Carter, A.S., Volkmar, F.R. & Sparrow, S.S. (2000). "Toward a Developmental Operational Definition of Autism." Journal of Autism and Developmental Disorders 30(4): 269-278.
- Gilson, S. F., & Depoy, E. (2000). "Multiculturalism and disability: a critical perspective." Disability & Society 15(2): 207-218.
- Gilstrap, L. L. (2004). "A Missing link in suggestibility research: what is known about the behavior of field interviewers in unstructured interviews with young children?" Journal of Experimental Psychology: Applied 10(1): 13-24.
- Glasberg, B. A. (2000). "The Development of siblings' understanding of autistic spectrum disorder." Journal of Autism and Developmental Disorders 30(2): 143-156.
- Glaser, B. G. (1992). Basics of Grounded Theory Analysis: emergence vs forcing. Mill Valley, CA: Sociology Press.
- Goffman, E. (1963). Stigma: Notes on the Management of Spoiled Identity. NJ, Englewood Cliffs: Prentice-Hall.
- Gold, N. (1993). "Depression and social adjustment in siblings of boys with autism." Journal of Autism & Developmental Disorders 30(2): 143-156.
- Goldman-Segall, R. (1998). Point of Viewing Children's Thinking. NJ, Mahwah: Lawrence Erlbaum Associates.
- Goldman, R. (2004). "Video perspectivity meets wild and crazy teens: a design ethnography." Cambridge Journal of Education 34(2): 157-178.
- Gladstone, B.M., Boydell, K.M., & McKeever, P. (2006) "Recasting research into children's experiences of parental mental illness: beyond risk and resilience." Social Science & Medicine. 62(10) 2540-2550
- Gordon, D., Parker, R., Loughran, F., & Heslop, P. (2000). Disabled children in Britain: a re-analysis of the OPCS disability surveys. London: The Stationery Office.
- Goodenough, T., Williamson, E., Kent, J. & Ashcroft, R. (2004) Ethical Protection: Participants' Views. Including Children in the Debate. In Smyth, M. & Williamson, E.

(eds.) Researchers and their 'Subjects': ethics, power, knowledge and consent. Bristol: Policy Press. 55-72

Grasseni, C. (2004). Video and ethnographic knowledge: skilled vision in the practice of breeding. In: S. Pink, L. Kürti, & A. I. Afons (Eds.) Working images: visual research and representation in ethnography. London: Routledge: 15-30.

Gray, D. E. (1993). "Perceptions of stigma: the parents of autistic children." Sociology of Health & Illness 15(1): 102-120.

Gray, D. E. (1997). "High functioning autistic children and the construction of "normal family life." Social Science & Medicine 44(8): 1030-1044.

Gray, D. E., & Holden, W.J. (1992). "Psychosocial well-being among the caregivers of children with autism." Australia and New Zealand Journal of Developmental Disabilities 18(2): 83-93.

Greenberg, J. S., Seltzer, M.M., Orsmond, G.I., & Krauss, M.W. (1999). "Siblings of adults with mental illness or Mental Retardation: current involvement and expectation of future caregiving." Psychiatric Services 50(9): 1214-1219.

Greenfield, P. M., Keller, H., Fuligni, A., & Maynard, A. (2003). "Cultural pathways through universal development." Annual Review of Psychology 54: 461-490.

Greenspan, S. I. (2001). "Working with siblings of children with learning challenges." Scholastic Early Childhood Today 15(7): 22.

Grey, K. M., & Tonge, B.J. (2001). "Are there early features of autism in infants and preschool children?" Journal of Paediatrics and Child Health 37(3): 221-226.

Grinker, R. R. (2007). Unstrange Minds: remapping the world of autism. NY: Basic Books.

Grissom, M. O., & Borkowski, J.G. (2002). "Self-efficacy in adolescents who have siblings with or without disabilities." American Journal on Mental Retardation 107(2): 79-90.

Groce, N. E. (2000) Framing disability issues in local concepts and beliefs. Asia Pacific Disability Rehabilitation Journal 10(1)  
<http://www.dinf.ne.jp/doc/english/asia/resource/apdrj/z13jo0300/z13jo0303.html>  
Access date: 20/3/2008

Grossman, F. K. (1972). Brothers and sisters of retarded children: an exploratory study. Syracuse, NY: Syracuse University Press.

Grover, S. (2004). "Why won't they listen to us? on giving power and voice to children participating in social research." Childhood 11(1): 81-93.

- Grundy, E., & Henretta, J. (2006). "Between elderly parents and adult children: a new look at the intergenerational care provided by the 'sandwich generation'." Ageing & Society 26(5): 707-722.
- Gudykunst, W. B., Matsumoto, Y., Ting-Toomey, S., Nishida, T., Kim, K., & Heyman, S. (1996). "The influence of cultural individualism–collectivism, self construals, and individual values on communication styles across cultures." Human Communication Research 22(4): 510-543.
- Guite, J. W., Lobato, D., Kao, B., & Plante, W. (2004). "Discordance between sibling and parent reports of the impact of chronic illness and disability on siblings." Children's Health Care 33(1): 77-92.
- Gupta, A., & Singhal, N. (2005). "Psychosocial support for families of children with autism." Asia Pacific Disability Rehabilitation Journal 16(2): 62-83.
- Hahm, C. B. (2003). Family versus the individual: the politics of marriage laws in Korea. In: D. A. Bell, & Hahm, C.B. (Eds.) Confucianism for the Modern World. Cambridge: Cambridge University Press: 334-360.
- Hahm, H.C. & Guterman, N.B. (2001) "The emerging problem of physical child abuse in South Korea," Child Maltreatment 6(2), 169–179.
- Hames, A. (1998). "Do younger siblings of learning-disabled children see them as similar or different?" Child: Care, Health and Development 24(2): 157-168.
- Hames, A. (2007). "Siblings' understanding of learning disability: a longitudinal study." Journal of Applied Research in Intellectual Disabilities OnlineEarly Article.
- Hammersley, M. (1998). Reading Ethnographic Research: a critical guide. London: Longman.
- Hammersley, M., & Atkinson, P. (1996). Ethnography: principles in practice. London: Routledge.
- Hand, J. E., Trewby, M., & Reid, P.M. (1994). "When a family member has an intellectual handicap." Disability & Society 9(2): 167-184.
- Hannah, M. E., & Midlarsky, E. (1999). "Competence and adjustment of siblings of children with mental retardation." American Journal on Mental Retardation, 104(1): 22-37.
- Hannah, M. E., & Midlarsky, E. (2005). "Helping by siblings of children with Mental Retardation." American Journal on Mental Retardation 110(2): 87-99.
- Harden, J., Scott, S., Backett-Milburn, K., & Jackson, S. (2000). "Can't Talk, Won't Talk? Methodological Issues in Researching Children." Sociological Research Online 5(2): <http://www.socresonline.org.uk/5/2/harden.html>. Access date: 6/4/2006



- Hardman, C. (2001). "Can there be an Anthropology of Children?" Childhood 8(4): 501-517.
- Hare-Mustin, R. T. (1994). "Discourses in the mirrored room: a postmodern analysis of therapy." Family Process 33(1): 19-33.
- Harkness, J. A. (2003). Questionnaire translation. In: J. A. Harkness, F.J.R., Van de Vijver, & P.P. Mohler (Eds.) Cross-Cultural Survey Methods. NJ: John Wiley & Sons: 35-56.
- Harland, P., & Cuskelly, M. (2000). "The Responsibilities of adult siblings of adults with dual sensory impairments." International Journal of Disability, Development and Education, 47(3): 293-307.
- Harper, D. (1998). Reimagining Visual Methods: Galileo to neuromancer. In: N. K. Denzin, & Y. Lincoln (Eds.) Handbook of Qualitative research. Thousand Oaks, CA: Sage: 717-732.
- Harris, S. L. (1994). Siblings of Children with Autism: a guide for families. Bethesda, MD: Woodbine house.
- Harrison, B. (2002). "Seeing health and illness worlds - using visual methodologies in a sociology of health and illness: a methodological review." Sociology of Health & Illness 24(6): 856-872.
- Hart, R. (1997a). Children's Participation: From Tokensim to Citizenship. London: Earthscan/UNICEF.
- Hart, R. (1997b). Children's Participation: the theory and practice of involving young citizens in community development and environmental care. London: Earthscan.
- Harwood, V. (2006). Diagnosing 'Disorderly' Children: a critique of behaviour disorder discourses. London: Routledge.
- Hastings, R. P. (2003a). "Breif report: behavioral adjustment of siblings of children with autism." Journal of Autism & Developmental Disorders 33(1): 99-104.
- Hastings, R. P. (2003b). "Behavioral adjustment of siblings of children with autism engaged in applied behavioral analysis early intervention programs: the moderating role of social support." Journal of Autism and Developmental Disorders, 33(2): 141-150.
- Hastings, R. P., Kovshoff, H., Ward, N.J., Espinosa, F.D., Brown, T., & Remington, B. (2006). "Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism." Journal of Autism and Developmental Disorders 35(5): 635-644.
- Heath, C., & Hindmarsh, J. (2002). Analysing interaction: video, ethnography and situated conduct. In: T. May (Ed.) Qualitative Research in Action. London: Sage: 99-121.

- Heckathorn, D. D. (2002). "Respondent-driven sampling II: deriving valid population estimates from chain-referral samples of hidden populations." Social Problems 49(1): 11-34.
- Hendrick, H. (2000). The Child as a Social Actor in Historical Sources. In: P. Christensen, & A. James (Eds.) Research with Children: Perspectives and Practices. London: Falmer Press: 36-61.
- Higgins, D. J., Bailey, S.R., & Pearce, J. C. (2005). "Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder." Autism 9(2): 125-137.
- Hill, E. L., & Frith, U. (2003). "Understanding autism: insights from mind and brain." Philosophical Transactions: Biological Sciences, 358(1430): 281-289.
- Hill, M. (1997). "Participatory research with children." Child and Family Social Work 2(3): 171-183.
- Hill, M. (2005). Ethical considerations in researching children's experiences. Researching Children's Experience: approaches and methods. S. Greene, & Hogan, D. London, Sage: 61-86.
- Hirst, M. (2001). "Trends in informal care in Great Britain during the 1990s." Health and Social Care in the Community 9(6) 348-357.
- Hodapp, R. M., Glidden, L.M., & Kaiser, A.P. (2005). "Siblings of persons with disabilities: toward a research agenda." Mental Retardation 43(5): 334-338.
- Hofstede, G. (1991) Cultures and Organizations: software of the mind. London: McGraw-Hill,
- Hogan, D. P., Park, J.M., & Goldscheider, F.K. (2003). "The health consequences of a disabled sibling for school-age children." Research in Social Science and Disability 3: 185-205.
- Holliday, I. (2005). "East Asian social policy in the wake of financial crisis: farewell to productivism." Policy and Politics 33(1): 145-162.
- Holliday, R. (2000). "We've been framed: visualising methodology." Sociological Review 48(4): 503-521.
- Holloway, S., & Valentine, Gill (2000a). Children's Geographies: Living, Playing and Transforming Everyday Worlds. London: Routledge.
- Holm, G. (2008) Visual research methods: where are we and where are we going? In: S. N. Hesse-Biber, & P. Leavy (Eds.) Handbook of Emergent Methods. NY: the Guilford press. 325-342

- Holtgraves, T. (1997). "Styles of Language Use: individual and cultural variability in conversational indirectness." Journal of Personality and Social Psychology 73(3): 624-637.
- Honey, A., & Halse, C. (2006). "Looking after well siblings of adolescent girls with anorexia: an important parental role." Child: care, health and development 33(1): 52-58.
- Hong, E. J. (2004). A Case Study of Group Art Therapy for the Stress Management of Children with Disabled Siblings. Weon-Gwang University. MA Dissertation. in Korean
- Hong, K. Z., & Song, H.K. (2006). "Continuity and change in the Korean welfare regime." Journal of Social Policy 35(2): 247-265.
- Hood, S., Kelley, P., & Mayall, B. (1996). "Children as research subjects: a risky enterprise." Children & Society 10(2): 117-128.
- Horwitz, A. V., Tessler, R. C., Fisher, G. A., & Gamade, G.M. (1992). "The role of adult siblings in providing social support to the severely mentally ill." Journal of Marriage and the Family 54(1): 233-241.
- Horwitz, A. V. (1993). "Siblings as caregivers for the seriously mentally ill." The Milbank Quarterly 71(2): 323-339.
- Horwitz, A. V., & Reinhard, S.C. (1995). "Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illness." Journal of Health & Social Behavior 36(2): 138-150.
- Horwitz, A. V., Tessler, R. C., Fisher, G. A., & Gamade, G.M. (1992). "The role of adult siblings in providing social support to the severely mentally ill." Journal of Marriage and the Family 54(1): 233-241.
- Houtzager, B., Grootenhuis, M., Caron, H., & Last, B. (2005). "Sibling self-report, parental proxies and quality of life: the importance of multiple informants for siblings of a critically ill child." Pediatric Hematology and Oncology 22(1): 25-40.
- Howard, S., Dryden, J., & Johnson, B. (1999) "Childhood resilience: review and critique of literature." Oxford Review of Education. 25(3) 307-323.
- Howlin, P. (1988). "Living with impairment: the effects on children of having an autistic." Child: Care, Health and Development 14(6): 395-408.
- Howlin, P. (2002). Children with Autism and Asperger Syndrome: a guide for practitioners and carers. Chichester: John Wiley & Sons.
- Hui, E. (2008). "Parental refusal of life-saving treatments for adolescents: Chinese familism in medical decision-making revisited." Bioethics Online Early View article.
- Hupcey, J. E. (1998). "Clarifying the social support theory-research linkage." Journal of Advanced Nursing, 27(6): 1231-1241.

- Hussain, Y. (2003). "Transitions into adulthood: disability, ethnicity and gender among British South Asians." Disability Studies Quarterly 23(2): 100-112.
- Hutchby, I. and Moran-Ellis, J. (1998) Situating children's social competence. In I. Hutchby & J. Moran-Ellis (Eds.) Children and Social Competence: arenas of action. London: Falmer. 7-26
- Hutson, S. P., & Alter, B.P. (2007). "Experiences of siblings of patients With Fanconi Anemia." Pediatric Blood & Cancer 48(1): 72-79.
- Hwang, K. K. (1997-8). "*Guanxi* and *mientze*: Conflict resolution in Chinese society." Intercultural Communication Studies VII (1) 17-42.
- Hwang, B. M. (2003). "The Effects of a Sibling-involved Language Intervention in Children with Language Disorders." Korean journal of speech sciences 10(3): 65-78. in Korean
- Hwang, H.J., & James-Roberts, I. (1998) "Emotional and Behavioural Problems in Primary School Children from Nuclear and Extended Families in Korea." Journal of Child Psychology & Psychiatry. 39(7) 973-979
- Hoppe-Graff, S., & Kim, H.O. (2004 ) Understanding rights and duties in different cultures and contexts: observations from German and Korean Adolescents. In: N.J. Finkel & F.M. Moghaddam, (Eds.) The Psychology of Rights and Duties: empirical contributions and normative commentaries, Washington: APA Press. 49-73
- Hyun, K. J. (2001). "Sociocultural change and traditional values: Confucian values among Koreans and Korean Americans." International Journal of Intercultural Relations. 25(2): 203-229.
- Im, E. O., Park, Y.S., Lee, E.O., & Yun, S.N. (2004). "Korean women's attitudes toward breast cancer screening tests." International Journal of Nursing Studies 41(6): 583-589.
- Ingstad, B., & Whyte, S.R., Ed. (1995). Disability and Culture. London: University of California Press.
- Innis, K., & Shaw, M. (1997). "How do students spend their time?" Quality Assurance in Education 5(2): 85-89.
- Ishizaki, Y., Ishizaki, T., Ozawa, K., Fukai, Y., Hattori, Y., Taniuchi, S., & Kabayashi, Y. (2005). "Psychosocial problems among siblings of children with disabilities in Japan: psychosocial association between mothers and siblings." Journal of Developmental and Physical Disabilities 17(2): 119-132.
- James, A. (1995). Methodologies of competence for a competent methodology. Children and Social Competence. Guildford: University of Surrey.

- James, A. (2001). Ethnography in the study of children and childhood. In: P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.) Handbook of Ethnography. London: Sage: 246-257.
- James, A., Jenks, C., & Prout, A. (1998). Theorizing Childhood. Cambridge: Polity Press.
- James, A. & Prout, A. (Eds.) (1997). Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood. London: Falmer Press.
- Jang, H. K., Hong, S.A., Kim, Y.R., & Kim, S. J. (2005). A Study of Social supports for Care-working in Families. Korea, Seoul: Korean Women's Development Institute. in Korean
- Jang, H. K., Hong, S.A., Lee, S.W., Kim, Y.R., Kang, E.H., & Kim, G.E. (2006). Status Survery on Caregiving Work in Family. Korea, Seoul: The Korean Women's Development Institute. in Korean
- Järbrink, K., & Knapp, M. (2001). "The economic impact of autism in Britain." Autism 5(1): 7-22.
- Jefferson, G. (2004). Glossary of transcript symbols with an introduction. In: G. Lerner (Ed.) Conversation Analysis: studies from the first generation. Amsterdam: John Benjamins: 13-32.
- Jenkins, R. (1998). Culture, classification and (in)competence. In: R. Jenkins (Ed.) Questions of Competence: Culture, Classification and Intellectual Disability. Cambridge: Cambridge University Press: 1-24.
- Jenkins, S. P., Rigg, J.A., & Devicienti, F. (2001). The Dynamics of Poverty in Britain. Department for Work and Pensions. Research No.157. Leeds: Corporate Document Services.
- Jenks, C. (1996) Childhood. London: Routledge
- Jeon, G. Y., & Kim, S.K. (2005). "A Needs assessment and satisfaction level of family support services for preschoolers with disabilities." The Journal of Korean Home Economics Association 43(5): 57-79. in Korean
- Jeon, J. H. (2002). A Study on Stress Characteristics in Siblings of Students with Cerebral Palsy. Tae-Gu University. MA Dissertation. in Korean
- Jewell, T. C., & Stein, C. H. (2002). "Parental influence on sibling caregiving for people with severe mental illness." Community Mental Health Journal 38(1): 17-33.
- Jin, M. S. (2001). The Influence of Family Environment of Children with Disabilities on their Sibling with Non-Disabilities. Che-Ju University. MA Dissertation. in Korean

Jodl, K. M., Bridges, M., Kim, J. E., Mitchell, A. S., & Chan, R. W. (1999). "Relations among relationships: a family systems perspective." Adolescent siblings in stepfamilies: family functioning and adolescent adjustment, *Monographs of the Society for Research in Child Development* 64(4): 150-183.

Johnson, J., & Bytheway, B. (2001). "An Evaluation of the use of diaries in the study of medication in later life." International Journal of Social Research Methodology 4(3): 183-204.

Johnson, K. (2004). Researching with children: Children's perspectives of their place(s) in Primary Schools. Australian Association for Research in Education Conference, Melbourne.

Johnson, V., Ivan-Smith, E., Gordon, G., Pridmore, P., Scott, P., Chambers, R., & Ennew, J. (1998). Stepping Forward: Children and young people's participation in the development process. London: Intermediate Technology.

Jones, A., Jeyasingham, D., & Rajasooriya, S. (2002). Invisible Families: the strengths and needs of black families in which young people have caring responsibilities. Bristol: The Policy Press.

Jones, K. (2006). "Informal care as relationship: the case of the Magnificent Seven." Journal of Psychiatric and Mental Health Nursing 13(2): 214-220.

Jones, L., & McNamara, O. (2004). "The Possibilities and constraints of multimedia as a basis for critical reflection." Cambridge Journal of Education 34(3): 279-296.

Jun, J. H. (2002). A Study on Stress Characteristics in Siblings of Students with Cerebral Palsy. Taegu University. MA Dissertation. in Korean

Jung, D. Y. (2002). "The Issues and Tasks in the Concept and Diagnostic Assessment of Learning Disabilities." Journal of Emotional Disturbances & Learning Disabilities 18(1): 63-87. in Korean

Jung, D. Y. (2007). "South Korean perspective on Learning Disabilities." Learning Disabilities Research & Practice 22(3): 183-188.

Jung, S. J. (2004). A Study on the Adaptation and the Social Support of the Mother with an Autistic Child. Sil-La University. MA Dissertation. in Korean

Kadesjö, B., Gillberg, C., & Hagberg, B. (1999). "Brief Report: Autism and Asperger Syndrome in Seven-Year-Old Children: A Total Population Study." Journal of Autism and Developmental Disorders 29(4): 327-331.

Kağitçibasi, C. (1997). Individualism and Collectivism. In: J.W. Berry., M.H. Segall, C. Kağitçibas (Eds.) Handbook of Cross-Cultural Psychology: social behavior and applications. Vol.3. Boston: Allyn and Bacon. 1-50

Kaminsky, L., & Dewey, D. (2001). "Siblings relationships of children with autism." Journal of Autism and Developmental Disorders 31(4): 399-410.

- Kaminsky, L., & Dewey, D. (2002). "Psychosocial adjustment in siblings of children with autism." Journal of Child Psychology & Psychiatry 43(2): 225-232.
- Kan, M. Y. (2006). Measuring Housework Participation: the gap between "Stylised" questionnaire estimates and diary-based estimates, Institute for Social and Economic Research University of Essex. <http://www.genet.ac.uk/workpapers/GeNet2006p20.pdf>  
Access date: 4/7/2007
- Kang, K. S. (2007). "Current status and prospects on collaboration among related agencies in providing appropriate services for the individuals with disabilities." Journal of Special Education in the Asia Pacific 3: 24-35.
- Kang, Y. S. (2004). Social Welfare for The Disabled. Seoul: Shin-Jeong. in Korean
- Kaomea, J. (2003). "Reading erasures and making the familiar strange: defamiliarizing methods for research in formerly colonized and historically oppressed communities." Educational Researcher 32(2): 14-25.
- Kaplan, F. (1969). Siblings of the retarded. Psychological Problems in Mental Deficiency. S. B. Sareson, & Doris, J. New York, Harper & Row: 186-208.
- Karasik, P., & Karasik, J. (2003). The Ride Together: a brother and sister's memoir of autism in the family. New York, Washington Square Press.
- Katbamna, S., Ahmad, W., Bhakta, P., Baker, R., & Parker, G. (2004). "Do they look after their own? informal support for South Asian carers." Health and Social Care in the Community 12(5): 398-406.
- Katbamna, S., Bhakta, P., & Parker, G. (2000). Perceptions of disability and care-giving relationships in South Asian communities. In: W. I. U. Ahmad (Ed.) Ethnicity, disability, and chronic illness. Buckingham: Open University Press: 12-27.
- Kawamura, T., Kono, Y., Kidode, M. (2002). Wearable Interfaces for a Video Diary: Towards Memory Retrieval, Exchange, and Transportation. Sixth International Symposium on Wearable Computers (ISWC'02). <http://tatsuyuki.kawamura-san.com/publications/iswc2002.pdf> Access date: 3/4/2006
- Keith, L., & Morris, J. (1995). "Easy targets: a disability rights perspective on the "children as carers" debate." Critical Social Policy 15(43): 36-57.
- Kellett, M. (2005a). How to Develop Children as Researchers: a step-by-step guide to teaching the research process. London: Paul Chapman Publishing.
- Kellett, M. (2005b). Children as active researchers: a new research paradigm for the 21st century? ESRC National Centre for Research Methods.

- Kellett, M., Forrest, R., Dent, N., & Ward, S. (2004). "Just teach us the skills please, we'll do the rest: empowering ten-year-olds as active researchers." Children & Society 18(5): 329-343.
- Kendall, J. (1999). "Sibling accounts of Attention Deficit Hyperactivity Disorder (ADHD)." Family Process 38(1): 117-136.
- Kendrick, M., & McKay, R. (2004). "Drawing as alternative way of understanding young children's constructions of literacy." Journal of Early Childhood Literacy 4(1): 109-128.
- Kerstein, L. H., & Gabriels, R.L. (2002). Sib to Sib - making connections: a psychoeducational sibling support group. In: R. L. Gabriels, & D.E. Hill, (Eds.) Autism: from research to individualized practice. London: Jessica Kingsley Publishers: 207-230.
- Keum, J. T. (2000). Confucianism and Korean thoughts. Korea, Seoul: Jimoondang.
- Kim-Rupnow, W. S. (2001). An Introduction to Korean Culture for Rehabilitation Service Providers. NY, Buffalo: Center for International Rehabilitation Research Information and Exchange.
- Kim-Rupnow, W. S. (2005). Disability and Korean culture. In: J. H. Stone (Ed.) Culture and Disability: Providing Culturally Competent Service. London: Sage: 115-138.
- Kim, A. Y., & Lim, E.Y. (1999). How Critical Is Back Translation in Cross-Cultural Adaptation of Attitude Measures? the Annual Meeting of the American Educational Research Association, Montreal, Quebec, Canada.
- Kim, C. W., & Dembo M.H (2000). "Social-cognitive factors influencing success on college entrance exams in South Korea." Social Psychology of Education 4(2): 95-115.
- Kim, E. H. (1998). The Social reality of Korean American women: toward crashing with the Confucian ideology. In: Y. I. Song, & Moon, A. (Eds.) Korean American Women: from tradition to modern feminism. Westport, CT: Praeger: 23-34.
- Kim, E. J. (2006). History of disability: Korea. In: G. L. Albrecht, D.T Mitchell, S.L. Snyder, J.Bickenbach, & W.O. Schalick, (Eds.) Encyclopedia of Disability. Thousand Oaks, CA: Sage. 2: 858-864.
- Kim, H. J. (2004). A Study on the Influence of Support Programs for the Siblings with Disabilities on the Self-Concept & Siblings Relationships of Siblings without Disabilities. Dan-Kook University. MA Dissertation. in Korean
- Kim, H. J. (2005). "Educational supports for children with multiple disability in Korea." Journal of Special Education in the Asia Pacific 1: 14-20.
- Kim, H. K. (1998). A Study on Interaction between Family and Children with ADHD. Tae-Gu University. MA Dissertation. in Korean



Kim, H. O., & Hoppe-Graff, S. (2001). "Mothers roles in traditional and modern Korean families: the consequences for parental practices and adolescent socialization." Asia Pacific Education Review 2(1): 85-93.

Kim, H. R. (2006). A Study on Stress of Nondisabled siblings of Children with Mental Retardation According to Factors of Same School Participation, Birth Order, Gender. Dan-Kook University. MA Dissertation. in Korean

Kim, I. J., Kim, L.I.C., & Kelly, J.G. (2006). "Developing cultural competence in working with Korean immigrant families." Journal of Community Psychology 34(2): 149-165.

Kim, J. H., & Theis, S.L. (2000). "Korean American Caregivers: who are they?" Journal of Transcultural Nursing, 11(4): 264-273.

Kim, J. S. (2001). "Daughters-in-law in Korean caregiving families." Journal of Advanced Nursing 36(3): 399-408.

Kim, J. S., & Lee, E.H. (2003). "Cultural and noncultural predictors of health outcomes in Korean daughter and daughter-in-law caregivers." Public Health Nursing 20(2): 111-119.

Kim, J. W., & Davis, A. (2006). "Korean disability employment policy: what is it offering people with learning disabilities?" Social Policy & Society 5(3): 409-419.

Kim, K. M. (2008). "The Current status and future of centres for independent living in Korea." Disability & Society 23(1): 67-76.

Kim, K. M., & Kim, M.O. (2006). "Analysis and implications on recent research articles' trends in Korean academy literature." Korean Journal of Social Welfare 58(3): 269-294. in Korean

Kim, S. H. (2003). "Korean cultural codes and communication." International Area Review 6(1): 93-114.

Kim, S. H. (2004). "The effects of the siblngs support program on nonhandicapped siblings' depression and behavior toward disabled sibling." The Journal of Special Children Education 6(1): 21-36. in Korean

Kim, S. H., Byun, Y.C., & Park, S.M. (2004). A Study of Anti-Discrimination for Promoting Integration of People with Disabilities. Report No 270-05. Seoul: KWDI/KIHASA. in Korean

Kim, S. H. (2007). "The Disabled Welfare Act Revision Bill and Its Significance." Welfare Forum 127: 34-40. in Korean

Kim, S. J., & Kang, K.A. (2003). "Meaning of life for adolescents with a physical disability in Korea." Journal of Advanced Nursing 43(2): 145-155.

- Kim, S. K., & Finch, J. (2002). "Confucian patriarchy reexamined: Korean families and the IMF economic crisis." The Good Society 11(3): 43-49.
- Kim, S. Y., & Min, S.Y. (2006). "Factors affecting the level of depression and life satisfaction of family caregivers of frail older people in Korea." Social Policy & Society 5(3): 399-408.
- Kim, T. Y. (2003). "Neo-Confucian body techniques: women's bodies in Korea's consumer society." Body & Society 9(2): 97-113.
- Kim, U. C. (2001). Ethnography of Korean people and culture. In: H. S. Aasen, Kim, U.C., & G. Helgesen, (Eds.) Democracy, Human Rights and Peace in Korea: psychological, political and cultural perspectives. Korea, Seoul: Kyoyook-Kwahak-Sa: 245-278.
- Kim, U. C., & Park, Y.S (2006). "Indigenous psychological analysis of academic achievement in Korea: the influence of self efficacy, parents, and culture." International Journal of Psychology 41(4): 287-291.
- Kim, Y. D. (2002). "Changes in the concept of disability and its implications for social work practice." Korean Journal of Social Welfare 51: 157-182. in Korean
- Kim, Y. D. (2005a). Theory of teamwork and system of community care centre in Korea. In: Kim, Y. D. & Yoo, D.C. (Eds.) The understanding of welfare for people with disabilities in Korea. Korea, Seoul: Ingan-gwa-Bokji: 327-355. in Korean
- Kim, Y. D. (2005b). "Issues on user participation in Korean disability services: implications from UK community care." Korean Journal of Social Welfare 57(3): 363-387. in Korean
- Kim, Y. D., & Ross, L. (2008). "Developing service user involvement in the South Korean disability services: lessons from the experience of community care policy and practice in UK." Health and Social Care in the Community 16(2): 188-196.
- Kim, Y. D., & Ross, L. (2007). "Developing service user involvement in the South Korean disability services: lessons from the experience of community care policy and practice in UK." Health & Social Care in the Community OnlineEarly Article.
- Kim, Y. D., & Lee, J.S. (2005). Assessment and support services in community care centre. In: Kim, Y.D., & Yoo, D.C. (Eds.) The understanding of welfare for people with disabilities in Korea. Korea, Seoul: Ingan-gwa-Bokji: 311-325. in Korean
- Kim, Y. G. (2002). "The Confucian-Christian context in Korean Christianity." B.C. Asian Review 13: 70-91.
- Kim, Y. H. (2003). "Productive Welfare: Korea's third way?" International Journal of Social Welfare 12(1): 61-67.

Kim, Y. M. (2006). *Toward a comprehensive welfare state in South Korea: institutional features, new social and political pressures, and the possibility of the welfare state*. London: Asia Research Centre, London School of Economics and Political Science.

Kim, Y. M. (2008). "Beyond East Asian welfare productivism in South Korea." Policy & Politics 36(1): 109-125.

Kim, Y. R. (2002). Korea, the nation of calm 'jeong'. In: Lim, T. S. (Ed.) Jeong, Chemyon, Yonjul and the human relationship of Korean. Korea, Seoul: Han-Na-Rae: 13-34. in Korean

Kim, Y. S. (2001). "Research on the brothers and sisters of children with special needs in Family-relationship." Journal of Mental Retardation 3: 145-159. in Korean

Kindon, S. (2003). "Participatory video in geographic research: a feminist practice of looking?" Area 35(2): 142-153.

King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A. (2006). "A qualitative investigation of changes in the belief systems of families of children with Autism or Down syndrome." Child: Care, Health & Development 32(3): 353-369.

Kirk, J., & Miller, M.L. (1986). Reliability and Validity in Qualitative Research. London: Sage.

Kleinman, J. M., Ventola, P.E., Pandey, J., Verbalis, A.D., Barton, J., Hodgson, S., Green, J., Dumont-Mathieu, T., Robins, D.L., & Fein, D. (2008). "Diagnostic stability in very young children with autism spectrum disorders." Journal of Autism and Developmental Disorders 38(4): 606-615.

Klin, A., Lang, J., Cicchetti, D.V., & Volkmar, F.R. (2000). "Brief report: interrater reliability of clinical diagnosis and DSM-IV criteria for autistic disorder: results of the DSM-IV autism field trial." Journal of Autism and Developmental Disorders 30(2): 163-167.

Knott, F., Aline-Wendy, D., & Mackay, T. (2006). "Living with ASD: how do children and their parents assess their difficulties with social interaction and understanding?" Autism 10(6): 609-617.

Knott, F., Lewis, C. & Williams, T. (1995). "Sibling interaction fo children with learning disabilities: a comparison of autism and down's syndrome." Journal of Child Psychology and Psychiarty 36(6): 965-976.

Knott, F., Lewis, C., & Williams, T. (2007). "Sibling Interaction of Children with Autism: Development Over 12 Months." Journal of Autism and Developmental Disorders 37(10): 1987-1995.

Koo, J. H. (2007). The Analysis on the life experience of non-disabled siblngs with disabled children based on Grounded Theory. Chang-Won University. MA Dissertation. in Korean

- Korea National Statistical Office (KNSO) (2007). 2007 Report on The Korean Youth Statistics Survey. Seoul: KNSO. in Korean
- Kuhnle, S. (2007). Which way forward for Korea's welfare state? Is the nation ready to face higher taxes necessary to finance more state support? The Korea Herald. 18th July 2007
- Kweon, S. I. (1998). "The extended family in contemporary Korea: changing patterns of co-residence." Korea Journal 38(3): 57-67.
- Kwon, H. S. (2005). "Inclusion in South Korea: the current situation and future directions." International Journal of Disability, Development and Education 52(1): 59-68.
- Kwon, J. O. (2001). A Study on the Self-Concept of the Handicapped's Siblings. Mok-Won University. Master Dissertation. in Korean
- Kwon, M. O. (2000). "A literature review study about viewpoint for people with disabilities according to history change." The Journal of Special Education 35(3): 107-136. in Korean
- Kwon, S. M., & Holliday, I. (2007). "The Korean welfare state: a paradox of expansion in an era of globalisation and economic crisis." International Journal of Social Welfare 16(3): 242-248.
- Lähteenmäki, P. M., Sjöblom, J., Korhonen, T., & Salmi, T.T. (2004). "The siblings of childhood cancer patients need early support: a follow up study over the first year." Archives of Disease in Childhood 89(11): 1008-1013.
- Lainhart, J. E. (1999). "Psychiatric problems in individuals with autism, their parents and siblings." International Review of Psychiatry 11(4): 278-298.
- Lamorey, S. (1999). Parentification of Siblings of Children with Disability or Chronic Disease. In: D. Chase (Ed.) Burdened Children: theory, research and treatment of parentification. London: Sage. 75-91
- Lansdown, G. (1995). Taking Part: Children's participation in decision making. London: Institute for Public Policy Research.
- Lardieri, L. A., Blacher, J., & Swanson H.L. (2000). "Sibling relationships and parent stress in families of children with and without learning disabilities." Learning Disability Quarterly, 23(2): 105-116.
- Laurenceau, J.-P., & Bolger, N. (2005). "Using diary methods to study marital and family processes." Journal of Family Psychology 19(1): 86-97.
- Lavigne, J. V., & Ryan, M. (1979). "Psychologic adjustment of siblings of children with chronic illness." Pediatrics 63(4): 616-627.

- Lecavalier, L., Leone, S., & Wiltz, J. (2006). "The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders." Journal of Intellectual Disability Research 50(3): 172-183.
- LeCompte, M., & Goetz, J. (1982). "Problems of reliability and validity in ethnographic research." Review of Educational Research 52(1): 30-60.
- Lee, D. S. (2004). "Multiple paradigm of disability studies and the characteristic of welfare for the disabled in Korea on the focus of 'Welfare Law for the Disabled'." Korean Journal of Social Welfare, 56(3): 227-251. in Korean
- Lee, D. W. (2002). Affective Jeong and love. In: Lim, T. S. (Ed.) Jeong, Chemyon, Yonjul and the human relationship of Korean. Korea, Seoul: Han-Na-Rae: 35-56. in Korean
- Lee, E. E., & Farran, C.J. (2004). "Depression among Korean, Korean American, and Caucasian American family caregivers." Journal of Transcultural Nursing 15(1): 18-25.
- Lee, E. J. (2001). A Study of the Pattern of Nonhandicapped Children's Interaction with Their Handicapped Sibling. Sung-Kyun-Kwan University. MA Dissertation. in Korean
- Lee, E.O., Kim, H.S., Park, Y.S., Song, M., Lee, I., & Park, Y.H. (1999) "Model Development of Change of Family Functioning with Chronic Illness." Journal of Korean Academy of Nursing. 29(3) 467-484 in Korean
- Lee, G. Y. (2005). Relationship between the Parenting Burden and the Time Management Strategy of Employed Mothers with Disabled Children: focused on mothers using the educare center for the disabled children. Soong-Sil University. Ph.D Thesis. in Korean
- Lee, H. B. (2000). A Study on the Awareness and Attitude Toward the People with Disability: focused on the social workers in Kangsuh-Gu. Hangeung University. MA Dissertation. in Korean
- Lee, H. J., Kang, H.G., Seo, M.H., Chung, K.H., Yoo, D.C., Chung, J.H., Lee, S.K., Nho, E.J., & Hyun, M.I. (2003). Analysis of Public Assistance and Social Welfare Services: for a new framework. Korea, Seoul: KIHASA. in Korean
- Lee, H. K. (2005). Civil society and welfare reforms in post-crisis South Korea. The Canada-Korean Social Policy Symposium II. Canada, Toronto.
- Lee, H. S., & Kang, W.Y. (1997). "A study on needs and supports for the families of children with autism." Journal of Special Education 20: 96-120.
- Lee, H. S., & Ok, S.W. (2002). "Family of origin influences on anxiety, open communication, and relationship satisfaction: A test of Bowenian theory of anxiety as a mediator in the intergenerational transmission." Journal of Korean Home Economics Association 3(1): 111-126. in Korean

- Lee, H. W., Kwon, M.O., & Seo, E.J. (2001). "Social support for parents of children with disabilities." Journal of Special Education & Rehabilitation Science 40(1): 193-217. in Korean
- Lee, I. S. (2001). The Attitudes of Non-Disabled Siblings Toward Their Disabled Sibling. Woo-Suk University. MA Dissertation. in Korean
- Lee, I. S., Lee, E.O., Kim, H.S.S., Park, Y.S., Song, M.S., & Park, Y.H. (2004). "Concept development of family resilience: a study of Korean families with a chronically ill child." Journal of Clinical Nursing 13(5) 636-645
- Lee, I. S., Lee, E.O., Kim, H.S.S., Park, Y.S., Song, M.S., & Park, Y.H. (2006). "To Holroyd E (2005) Commentary on Lee et al. (2004)." Journal of Clinical Nursing 15(5): 654-656.
- Lee, I. S., Lee, E.O., Kim, H.S.S., Park, Y.S., Song, M.S., & Park, Y.H. (2004). "Concept development of family resilience: a study of Korean families with a chronically ill child." Journal of Clinical Nursing 13(5): 636-645.
- Lee, J. G. (2002) The Five-year plan for the promotion of the welfare of disabled people: progress assessment and future direction. Welfare Forum 65 in Korean
- Lee, J. H. (2003). "Rational rendering of Confucian relationships in contemporary Korea." Korea Journal 43(2): 257-288.
- Lee, J. K. (2002). "The five-year plan for the promotion of the welfare of disabled people: progress assessment and future direction." Policy Forum 65. in Korean
- Lee, K. K. (1998). Confucian tradition in the contemporary Korean family. In: W. H. Slote, & G.A. DeVos (Eds.) Confuciansim and The Family. NY: State University of New York Press: 249-266.
- Lee, M. H., Choi, K C., Lee, W. R., Kim, M. K., & Choi, S.A. (2004). "The Emotional problems of family having children with disabilities in daily life." Journal of Special Education & Rehabilitation Science 43(1): 137-158. in Korean
- Lee, S. H. (2002). "A Review on the prevalence of emotional, behavioral disorder and autistic spectrum disorder: focusing on the results of a survey on the prevalence of children with special needs conducted by the National Institute for Special Education in 2001." The Journal of the Special Education 23(2): 43-62. in Korean
- Lee, S. H. (2003). A Study on the Program Development for School-Age Children with Autistic Siblings. Seoul Women's University. MA Dissertation. in Korean
- Lee, S. H. (2006). The Effects of Sibling Support Programs on Sibling Relationship with the Children with Developmental Delays. Taegu University. MA Dissertation. in Korean

- Lee, S. W. (2005). "Economic situations of disabled people and alternative policies." Welfare Forum 114: 55-64. in Korean
- Lee, W. S. (2004). Social Work with Families. Korea, Seoul: Hakjisa. in Korean
- Lee, Y. H., & Kwon, J.U. (2002). "A Study on the burden of the handicapped's siblings: centred on Taejeon city area." Younsei Social Welfare Review 8: 59-85. in Korean
- Lee, Y. R., & Sung, K. T. (1998). "Cultural influences on caregiving burden: cases of Koreans and Americans." International Journal of Aging and Human Development 46(2): 125-141.
- Lee, Z. N. (1999). "Korean culture and sense of shame." Transcultural Psychiatry 36(2): 181-194.
- LeeKam, S. R., Libby, S.J., Wing, L., Gould, J., & Taylor, C. (2002). "The Diagnostic interview for social and communication disorders: algorithms for ICD-10 childhood autism and Wing and Gould autistic spectrum disorder." Journal of Child Psychology and Psychiatry 43(3): 327-342.
- Leem, H. K. (2002). The Adaptation Improvement Program for Non-disabled Siblings on the Families with Disabled Children. The Catholic University of Korea. MA Dissertation. in Korean
- Leininger, M. (2002) Anglo-American (United States) Culture care values, beliefs and lifeways. In: M. Leininger & M.R. Mcfarland, (Eds.) Transcultural Nursing: Concepts, theories, research and practice. 3<sup>rd</sup> ed. NY:McGraw-Hill Medical
- Levy-Wasser, N., & Katz, S. (2004). "The relationships between attachment style, birth order and adjustment in children who grow up with a sibling with mental retardation." The British Journal of Developmental Disabilities 50(2): 89-98.
- Lewis, V. (2003). Development and Disability. Oxford: Blackwell Publishing.
- Lim, T. S. (2002). Korea, the nation to venerate Che-myon. In: Lim, T. S. (Ed.) Jeong, Chemyon, Yonjul and the human relationship of Korean. Korea, Seoul: Han-Na-Rae: 101-128. in Korean
- Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic Inquiry. Newbury Park, CA: Sage.
- Lobato, D., Barbour, L., Hall, L. J., & Miller, C. T. (1987). "Psychosocial characteristics of preschool siblings of handicapped and nonhandicapped children." Journal of Abnormal Child Psychology 15(3): 329-338.
- Lobato, D., Faust, D., & Spirito, A. (1988). "Examining the effects of chronic disease and disability on children's sibling relationships." Journal of Pediatric Psychology 13(3): 389-407.

- Lobato, D. J. (1990). Brothers, Sisters and Special Needs: information and activities for helping young siblings of children with chronic illnesses and developmental disabilities. Baltimore, MD: Paul H. Brookes.
- Lobato, D. J., & Kao, B.T. (2002). "Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability." Journal of Pediatric Psychology, 27(8): 711-716.
- Lobato, D. J., Kao, B.T., & Plante, W. (2005). "Latino Sibling Knowledge and Adjustment to Chronic Disability." Journal of Family Psychology 19(4): 625-632.
- Lomax, H., & Casey, N. (1998). "Recording social life: Reflexivity and video methodology." Sociological Research Online 3(2): U3-U32.
- Lukemeyer, A., Meyers, M.K., & Smeeding, T. (2000). "Expensive children in poor families: out-of-pocket expenditures for the care of disabled and chronically ill children in welfare families." Journal of Marriage and the Family 62(2): 399-415.
- Luthar, S., Cicchetti, D., & Becker, B. (2000) "The construct of resilience: A critical evaluation and guidelines for future work." Child Development. 71(3) 543-562
- Lutz, A. C., & Collins, J. L. (1993). Reading National Geographic. Chicago, IL: University of Chicago Press.
- Lynch, D. J., Fay, L., Funk, J., & Nagel, R. (1993). "Siblings of children with mental retardation: Family characteristics and adjustment." Journal of Child and Family Studies 2(2): 87-96.
- Lynch, E. W., & Hanson, M.J. (2004). Developing Cross Cultural Competence. Baltimore, Maryland: Paul H. Brookes Publishing Company.
- Macks, R. J., & Reeve, R.E. (2007). "The Adjustment of non-disabled siblings of children with autism." Journal of Autism and Developmental Disorders 37(6): 1060-1067.
- MacNaughton, G., Smith, K., & Davis, K. (2007). Researching with children: the challenges and possibilities for building 'child friendly' research. In: J. A. Hatch (Ed.). Early Childhood Qualitative Research. NY: Routledge: 167-184.
- Magnania, R., Sabinb, K., Saidela, T., & Heckathorn, D. (2005). "Review of sampling hard-to-reach and hidden populations for HIV surveillance." AIDS 19(suppl 2): S67-S72.
- Maguire, M. H. (2005). "What if you talked to me? I could be interesting! Ethical research considerations in engaging with bilingual / multilingual child participants in human inquiry." Forum: Qualitative Social Research 6(1). <http://www.qualitative-research.net/fqs-texte/1-05/05-1-4-e.htm#lit> Access date: 3/4/2006



- Maleki-Tehrani, M. (2006). Sibling Relationships and Family Dynamics in Families with a Child with Tourette Syndrome. Canada, University of Waterloo. PhD Thesis.
- Mandleco, B., Olsen, S.F., Dyches, T., & Marshall, E. (2003). "The relationship between family and sibling functioning in families raising a child with a disability." Journal of Family Nursing 9(4): 365-396.
- Marciano, A. R. F., & Scheuer, C. I. (2005). "Quality of life in siblings of autistic patients." Revista Brasileira de Psiquiatria 27(1): 67-69.
- Marks, D. (1997). "Models of disability." Disability & Rehabilitation 19(3): 85-91.
- Marks, D. (1999). Disability: controversial debates and psychosocial perspectives. London: Routledge.
- Mason, P. (2005). "Visual data in applied qualitative research: lessons from experience." Qualitative Research 5(3): 325-346.
- Masson, J. (2000). Researching children's perspectives: legal issues. In: A. Lewis, & G. Lindsay (Eds.) Researching Children's Perspectives. Buckingham: Open University Press: 34-45.
- Masten, A. S. (2001). "Ordinary Magic: resilience processes in development." American Psychologist. 56 (3) 227-238.
- Mates, T. E. (1990). "Siblings of autistic children: their adjustment and performance at home and in school." Journal of Autism and Developmental Disorders 20(4): 545-553.
- Mayall, B. (1994). Children Action at Home and School. In: Mayall, B. (Ed.) Children's Childhoods: observed and experienced, Bristol: The Falmer Press. 114-127
- Mayall, B. (2000). Conversations with Children: Working with Generational Issues. In: P. Christensen, & A. James (Eds.) Research with Children London: Falmer Press: 120-135.
- McClure, L. (2001). "School-Age caregivers: perceptions of school nurses working in Central England." The Journal of School Nursing 17(2): 76-82.
- McCubbin, H. I., Thompson, E.A., Thompson, A.I., MCCubbin, M.A., & Kaston, A.J. (1993). "Culture, ethnicity, and the family: critical factors in childhood chronic illnesses and disabilities." Pediatrics 91(5): 1063-1070.
- McCusker, C. G., Kennedy, P.J., Anderson, J., Hicks, E.M., & Hanrahan, D. (2002). "Adjustment in children with intractable epilepsy: importance of seizure duration and family factors." Developmental Medicine & Child Neurology 44(10): 681-687.
- McGraw, L. A., & Walker, A.J. (2007). "Meaning of sisterhood and developmental disability: narratives from White nondisabled sisters." Journal of Family issues 28(4): 474-500.

McHale, S. M., & Gamble, W.C. (1987). "Sibling Relationships and Adjustment of Children with Disabled Brothers and Sisters." Journal of Children in Contemporary Society 19(3-4): 131-158.

McHale, S. M., & Gamble, W.C. (1989). "Sibling relationships of children with disabled and nondisabled brothers and sisters." Developmental Psychology 25(3): 421--429.

McHale, S. M., & Harris, V.S. (1992). Children's experiences with disabled and nondisabled siblings: links with personal adjustment and relationships evaluations. Children's Sibling Relationship: developmental and clinical issues. F. B. J. Dunn. Hillsdale, NJ, Lawrence Erlbaum Publishers: 83-100.

McHale, S. M., Simeonsson, R.J., & Sloan, J. (1984). Children with handicapped brothers and sisters. In: E. Schopler, & G. Mesibov (Eds.) The Effects of Autism in the Family. NY: Plenum: 327-342.

McHale, S. M., Sloan, J., & Simeonsson, R.J. (1986). "Sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters." Journal of Autism and Developmental Disorders 16(4): 399-413.

McHugh, M. (2003). Special Siblings: growing up with someone with a disability. Baltimore, MD: Paul. H. Brooks Publishing.

McKnight, C., Jarlais, D.D., Bramson, H., Tower, L., Abdul-Quader, A.S., Nemeth, C., & Heckathorn, D. (2006). "Respondent-driven sampling in a study of drug users in New York city: notes from the field." Journal of Urban Health 83(7): 54-59.

Mesibov, G. B., Shea, V., & Schopler, E. (2005). The TEACCH Approach to Autism Spectrum Disorders. NY: Kluwer Academic/Plenum Publishers.

Meyer, D. J. (1993). "Siblings children with special health and developmental needs: programs, services and considerations." ARCH fact sheet No.23, from <http://www.archrespite.org/archfs23.htm>. Access date: 4/5/2004

Meyer, D. J., & Vadasy, P.F. (1994). Sibshops: workshops for siblings of children with special needs. Maryland, Baltimore: Paul. H. Brooks.

Mihaylov, S. I., Jarvis, S.N, Colver, A.F., & Beresford, B. (2004). "Identification and description of environmental factors that influence participation of children with cerebral palsy." Developmental Medicine & Child Neurology 46(5): 299-304.

Miles, M. (2000). "Disability on a different model: glimpses of an Asian heritage." Disability & Society 15(4): 603-618.

Miller, P. (2001). "A study into the experiences of children who have a brother or sister with an autistic spectrum disorder." Good Autism Practice 2(2): 13-29.

- Miller, S. (1996) "Living with a disabled sibling – a review". *Paediatric Nursing*. 8 (8) 21–24.
- Mills, H. (2003). "Meeting the needs of black and minority ethnic young carers: a literature review and research study for the Willow Young Carers service". Barnardo's Policy, Research and Influencing Unit.
- Min, P. G. (2001). "Changes in Korean immigrants' gender role and social status, and their marital conflicts." *Sociological Forum* 16(2): 301-320.
- Min, Y. S. (2003). A Study on the between Social Supports and Stress which Non-Disabled Siblings Experience in a Family with Developmental Disabled Children. The Catholic University of Korea. MA Dissertation. in Korean
- Ministry Gender Equality & Family (MOGEF) (2006). Family is love and happy the parents-centred community. MOGEF: MOGEF. in Korean
- Ministry of Education & Human Resource (2003). The 2nd Special Education Development 5-years Plan. MOEH Resource: Ministry of Education & Human Resource. in Korean
- Ministry of Education & Human Resource (2006a). 2005 Status Survey on Special Education. M. o. E. H. Resource, Ministry of Education & Human Resource.
- Ministry of Education & Human Resource (2006b). Basic Research to Establish a Comprehensive Plan ('08-'12) for Special Education Improvement'. Ministry of Education & Human Resource. in Korean
- Ministry of Health & Welfare (2003). Diagnostic Criteria of Disability. MOHW: MOHW. in Korean
- Ministry of Health & Welfare (2005). The Welfare of Disabled Persons Act. MOHW, Seoul: MOHW. in Korean
- Ministry of Health & Welfare (2006a). The Status of Community Welfare Centre in 2006. MOHW: MOHW. in Korean
- Ministry of Health & Welfare (2006b). Basic tasks and goal of welfare policy for the disabled. MOHW: MOHW. in Korean
- Ministry of Health & Welfare (2007). Introducing 2007 Children Development Account. MOHW: MOHW. in Korean
- Ministry of Health & Welfare., Korea Council of Children's Organisations., The Korea Council for Children's Rights (2005). Monitoring Implementation of the Convention in Korea. MOHW: MOHW. in Korean
- Minuchin, S., Montalvo, B., Guerney, B.G., Rosman, B., & Schumer, F. (1967). Families of the Slums. NY: Basic Books.

- Mir, G., & Tovey, P. (2003). "Asian carers' experiences of medical and social care: the case of Cerebral Palsy." British Journal of Social Work, 33(4): 465-479.
- Miriam, D., Edvards, R., & Alldred, P. (2001). "Children and school-based research: 'informed consent' or 'educated consent'?" British Educational Research Journal 27(3): 347-365.
- Mirzoeff, N. (1999). An Introduction to Visual Culture. London, Routledge.
- Moll, L. C., (Ed.) (1990). Vygotsky and Education: instructional implications and applications of sociohistorical psychology. Cambridge: Cambridge Universtiy Press.
- Moore, M., Sixsmith, J., & Knowles, K., (Ed.) (1996). Children's Reflections on Family Life. London: Falmer Press.
- Moore, M. L., Howard, V.F., &McLaughli, T.F. (2002). "Siblings of children with disabilities: a review and analysis." International Journal of Special Education 17(1): 49-64.
- Morris, J. (1997). "A response to Aldridge & Becker—disability rights and the denial of young carers: the dangers of zerosum arguments." Critical Social Policy 17(3): 133-135.
- Morrow, W., & Richards, M. (1996). "The Ethics of social research with children: an overview." Children and Society 10(2): 90-100.
- Morse, J. M., & Pooler, C. (2002). "Analysis of videotaped data: methodological considerations." International Journal of Qualitative Methods, 1(4).  
<http://www.ualberta.ca/~ijqm/english/engframeset.html> Access date:14/7/2007
- Mullender, A., Hague, G., Imam, U., Kelly, L., Malos, E., & Regan, L. (2002). Children's Perspectives on Domestic Violence. London: Sage.
- Mulroy, S., Robertson, L., Aiberti, K., Leonard, H., & Bower, C. (2008). "The Impact of having a sibling with an intellectual disability: parental perspectives in two disorders." Journal of Intellectual Disability Research 52(3): 216-229.
- Mundy, P. (2003) "Annotation: The neural basis of social impairments in autism: the role of the dorsal medial-frontal cortex and anterior cingulate system." Journal of Child Psychology and Psychiatry 44(6) 793 - 809
- Murdick, N., Shore, P., Chittooran, M.M., & Gartin, B. (2004). "Cross-cultural comparision of the concept of 'otherness' and its impacton persons with disabilities." Education and Training in Developmental Disabilities 39(4): 310-316.
- Na, E. Y., & Duckitt, J. (2003). "Value consensus and diversity between generations and genders." Social Indicators Research 62 63(1-2): 411-435.

- Nam, S. J. (2002). Human & Welfare. Korea, Seoul: Han-Wool Academy. in Korean
- National Human Rights Commission of Korea (2002). Study of Improvement of Human Rights Awareness via Analysis and research of Disability Discriminatioin Status. NHRCK: NHRCK. in Korean
- National Initiative for Autism: Screening and Assessment (NIASA) (2003). National Autism Plan for Children. London: National Autistic Society.
- Naylor, A., & Prescott, P. (2004). "Invisible children? the need for support groups for siblings of disabled children." British Journal of Special Education 31(4): 199-206.
- Ncube, W. (1998). Law, Culture, Tradition and Children's Rights in Eastern and Southern Africa. Ashgate: Aldershot.
- Nehring, W. M. (2007). "Cultural considerations for children with intellectual and developmental disabilities." Journal of Pediatric Nursing 22(2): 93-102.
- Newman, T. (2003). Children of Disabled Parents: new thinking about families affected by disability and illness. Dorset: Russell House Publishing.
- Nicholson, H. N. (2001). "Seeing how it was? childhood geographies and memories in home movies." Area 33(2): 128-140.
- Nixon, C. L., & Cummings, E.M. (1999). "Sibling disability and children's reactivity to conflicts involving family members." Journal of Family Psychology 13(2): 274-285.
- Nolbris, M., & Hellström, A.L. (2005). "Siblings' needs and issues when a brother or sister dies of cancer." Journal of Pediatric Oncology Nursing 22(4): 227-233.
- Noyes, A. (2004). "Video Diary: a method for exploring learning dispositions." Cambridge Journal of Education 34(2): 193-209.
- O'Hara, J. (2003). "Learning disabilities and ethnicity: achieving cultural competence." Advances in Psychiatric Treatment 9(3): 166-176.
- O'Kane, C. (2000). The development of participatory techniques: facilitating children's views about decisions which affect them. In: P. Christensen, & A. James, (Eds.) Research with Children: perspectives and practices. London: Falmer Press: 136-159.
- Ochs, E., Kremer-Sadlik, T., Solomon, O., & Sirota, K. G. (2001). "Inclusion as social practice: views of children with autism." Social Development 10(3): 399-419.
- Oh, H. K., & Jun, H.Y. (2004). "A study on the degree of the burdens and the need of social support of family members with disabled children: focus on the life span of disabled children." Korean Journal of Family Welfare 9(1): 79-100.

- Oh, S. A. (2002). "Families of children with disabilities: the test of a structural model of family Income, hardiness, pile-up stress, communication, and family adaptation." Journal of the Korean Home Economics Association 40(9): 175-189. in Korean
- Oliva, A., & Arranz, E. (2005). "Sibling relationships during adolescence." European Journal of Developmental Psychology 2(3): 253-270.
- Oliver, M. (1990). The politics of disablement. Basingstoke: Macmillan.
- Oliver, M. (1996). Understanding Disability: from theory to practice. Basingstoke: Macmillan.
- Olsen, R. (1996). "Young carers: challenging the facts and politics of research into children and caring." Disability & Society 11(1): 41- 54.
- Olsen, R. (2000). "Families under the microscope: parallels between the Young Carers debate of the 1990s and the transformation of childhood in the late nineteenth century." Children & Society 14(5): 384-394.
- Olsen, R., & Parker, G. (1997). "A response to Aldridge and Becker-disability rights and the denial of young carers: the dangers of zero-sum arguments." Critical Social Policy 17(50): 125-133.
- Olsson, M. B., & Hwang, C.P. (2003). "The influence of macro structure of society on the life situation of families with a child with intellectual disability: Sweden as an example." Journal of Intellectual Disability Research 47(4/5): 328-341.
- Opperman, S., & Alant, E. (2003). "The coping responses of the adolescent siblings of children with severe disabilities." Disability & Rehabilitation 25(9): 441-454.
- Orsmond, G. I., & Seltzer, M.M. (2000). "Brothers and sisters of adults with Mental Retardation: gendered nature of the sibling relationship." American Journal on Mental Retardation 105(6): 486-507.
- Orsmond, G. I., & Seltzer, M. M. (2007a). "Siblings of individuals with autism spectrum disorders across the life course." Mental Retardation and Developmental Disabilities Research Reviews 13(4): 313-320.
- Orsmond, G. I., & Seltzer, M. M. (2007b). "Siblings of individuals with autism or Down syndrome: effects on adult lives." Journal of Intellectual Disability Research 51(9): 682-696.
- Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). "Relations between social support, appraisal and coping and both positive and negative outcomes in young carers." Journal of Health Psychology 12(1): 89-102.
- Park, B. J. (2001). "Patriarchy in Korean society: substance and appearance of power." Korea Journal 40(4): 48-73.

- Park, J. Y., Turnbull, A.P., & Turnbull III, H.R. (2002). "Impacts of poverty on quality of life in families of children with disabilities." Exceptional Children 68(2): 151-170.
- Park, M. J. (2006). "The Elements of happy families and it's meaning." Family & Culture 18(4): 183-205. in Korean
- Park, M. K. (1996). A Study of Siblings Support Programme for Children who Have Disabled Siblings. Soong-Sil University. MA Dissertation. in Korean
- Park, N. S., & Huebner, E.S. (2005). "A Cross-Cultural study of the levels and correlates of life satisfaction among adolescents." Journal of Cross-Cultural Psychology 33(4): 444-456.
- Park, S. W., Kwon, T.H., Woo, Y.G., Kim, U.J., Kim, H.I., & Han, H.M. (2006). Status Survey of Students with Special Educational Needs. Seoul: Korea Institute of Special Education. in Korean
- Park, T. H. (2004). "The influences of Familism on interpersonal trust of Korean public officials." International Review of Public Administration 9(1): 121-135.
- Park, W. (2006). Traditional Korean Thought. Korea, Incheon: Inha University Press.
- Park, Y. R. (2005). Gender dimensions of family policy in Korea. The Canada-Korea Social Policy Symposium II. Toronto, Canada.
- Patton, M. Q. (2002). Qualitative research & evaluation methods. Thousand Oaks, CA: Sage.
- Pearson, G. (1993). Talking a Good Fight: Authenticity and Distance in the Ethnographer's Craft. In: D. Hobbs, & T. May (Eds.) Interpreting the Field: Accounts of Ethnography. Oxford: Clarendon Press: vii-xx
- Penn-Edwards, S. (2004). "Visual Evidence in Qualitative Research: the Role of videorecording." The Qualitative Report 9(2): 266-277.
- Peters, S. (2000). "Is there a disability culture? a syncretisation of three possible world views." Disability & Society 15(4): 583-601.
- Petersen, R. D., & Valdez, A. (2005). "Using snowball-based methods in hidden populations to generate a randomized community sample of gang-affiliated adolescents." Youth Violence & Juvenile Justice 3(2): 151-167.
- Pettle, S. A., & Britten, C.M. (1995). "Talking with children about death and dying." Child: care, Health and Development 21(6): 395-404.
- Phuong-Mai, N., Terlouw, C., & Pilot, A. (2005). "Cooperative learning vs Confucian heritage culture's collectivism: confrontation to reveal some cultural conflicts and mismatch." Asia Europe Journal 3(3): 403-419.

- Pike, A., Coldwell, J., & Dunn, J. F. (2005). "Sibling relationships in early/middle childhood: links with individual adjustment." Journal of Family Psychology 19(4): 523-532.
- Pike, A., Manke, B., Reiss, D., & Plomin, R. (2000). "A genetic analysis of differential experiences of adolescent siblings across three years." Social Development 9(1): 96-114.
- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R.S. (2004). "Social and emotional adjustment of siblings of children with autism." Journal of Child Psychology & Psychiatry 45(4): 855-865.
- Pini, M. (2001). "Video diaries: questions of authenticity and fabrication." <http://www.latrobe.edu.au/screeningthepast/firstrelease/fr1201/mpfr13a.htm>. Access date: 3/4/2004,
- Pink, S. (2001a). "More visualising, more methodologies: on video, reflexivity and qualitative research." Sociological Review 49(4): 586-599.
- Pink, S. (2001b). Doing visual ethnography. London: SAGE.
- Pit-Ten Cate, I. M., & Loots, G.M.P.(Ineke) (2000). "Experiences of siblings of children with physical disabilities: an empirical investigation." Disability & Rehabilitation 22(9): 399-408.
- Pollack, E. G. (2002). "The childhood we have lost: when siblings were caregivers, 1900-1970." Journal of Social History 36(1): 31-61.
- Powell, J. E., Edwards, A., Edwards, M., Pandit, B.S., Sungum-Paliwal, S.R., & Whitehouse, W. (2000). "Changes in the incidence of childhood autism and other autistic spectrum disorders in preschool children from two areas in the West Midlands, UK." Developmental Medicine & Child Neurology 42(9): 624-628.
- Powell, T. H., & Gallagher, P.A. (2005). Brothers & Sisters: a special part of exceptional families. Maryland, Baltimore: Paul. H. Brookes.
- Priestley, M. (2001). Disability and the Life Course: global perspectives. Cambridge: Cambridge University Press.
- Priestley, M., Corker, M., & Watson, N. (1999) "Unfinished business: disabled children and disability identity." Disability Study Quarterly 19(2) 87-98
- Prior, M. (2003). "Is there an increase in the prevalence of autism spectrum disorders?" Journal of Paediatrics and Child Health 39(2): 81-82.
- Prosser, J. (1998). The Status of image-based research. In: J. Prosser (Ed.) Image based Research. London: Falmer Press: 97-112.
- Prout, A. (2000). "Children's participation: control and self-realisation in British late modernity." Children and Society 14(4): 304-315.



- Prout, A. (2001). "Representing children: reflections on the children 5–16 programme." Children and Society 15(3): 193-201.
- Prout, A., & James, A. (1997). A New Paradigm for the Sociology of Childhood? Provenance, Promise and Problems. In: A. James, & A. Prout (Eds.) Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood. 2<sup>nd</sup> Ed. London: Falmer Press.: 7-33.
- Pruchno, R. A. P., J.H. & Burant, C.J. (1996). "Aging Women and Their Children with Chronic Disabilities: Perceptions of Sibling Involvement and Effects on Well-Being." Family Relations 45(3): 318-326.
- Punch, K. F. (2005). Introduction to Social Research: quantitative and qualitative approaches. London: Sage.
- Punch, S. (2002a). "Interviewing Strategies with Young People: the 'Secret Box', Stimulus Material and Task-Based Activities." Children and Society 16(1): 45-56.
- Punch, S. (2002b). "Research with children: the same or different from research with adults." Childhood 9(3): 321-341.
- Quas, J.A., & Schaaf, J.M. (2002) "Children's memories of experienced and nonexperienced events following repeated interviews." Journal of Experimental Child Psychology. 83(4) 304-338
- Ramesh, M. (2003). Globalisation and social security expansion in East Asia. In: L. Weiss (Ed.) States in the Global Economy: bringing domestic institutions back in. Cambridge: Cambridge University Press.: 83-100.
- Rampton, T. B., Rosemann, J.L., Latta, A.L., Mandleco, B.L., Roper, S.O., & Dyches, T.T. (2007). "Images of life: siblings of children with Down Syndrome." Journal of Family Nursing 13(4): 420-442.
- Randall, P., & Parker., J. (1999). Supporting the Families of Children with Autism. Chichester: Wiley.
- Rao, S. (2006). "Parameters of normality and cultural constructions of 'mental retardation': perspectives of Bengali families." Disability & Society 21(2): 159-178.
- Ratcliffe, J. (2003). Listening to Siblings: the experiences of children and young people who have a brother or sister with a sever disability. Birmingham: the Handsel Trust.
- Receveur, C., Lenoir, P., Desombre, H., Roux, S., Barthelemy, C., & Malvy, J. (2005). "Interaction and imitation deficits from infancy to 4 years of age in children with autism: a pilot study based on videotapes." Autism 9(1): 69-82.
- Rich, M., & Chalfen, R. (1999). "Showing and telling asthma: children teaching physicians with visual narrative." Visual Sociology 14(1): 51-71.

- Rich, M., Lamola, S., Gordon, J., & Chalfen, R. (2000). "Video intervention/prevention assessment: a patient-centred methodology for understanding the adolescent illness experience." Journal of Adolescent Health 27(3): 155-165.
- Richards, J. C. (2006). "Post modern image-based research: an innovative data collection method for illuminating preservice teachers' developing perceptions in field-based courses." The Qualitative Report 11(1): 37-54.
- Rivers, J. W., & Stoneman, Z. (2003). "Sibling relationships when a child has autism: marital stress and support coping." Journal of Autism and Developmental Disorders 33(4): 383-394.
- Roberts, J. (2001) Dialogue, positionality and the legal framing of ethnographic research. Sociological Research Online 5(4) <http://www.socresonline.org.uk/5/4/roberts.html>  
Access date: 11/12/2004
- Robins, D., Fein, D., Barton, M., & Green, J. (2001). "The Modified checklist for autism in toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders." Journal of Autism & Developmental Disorders 31(2): 131-144.
- Robson, E. (2000). "Invisible carers: young people in Zimbabwe's home-based healthcare." Area 32(1): 56-69.
- Robson, E. (2004). "Hidden child workers: young carers in Zimbabwe." Antipode 36(2): 227-248.
- Robson, E., Ansell, N., Huber, U.S., Gould, W.T.S. & Van Blerk, L. (2006). "Young caregivers in the context of the HIV/AIDS pandemic in Sub-Saharan Africa." Population, Space and Place 12(2): 93-111.
- Rodgers, J (1999) "Trying to get it right: undertaking research involving people with learning difficulties" Disability and Society 14(4) 1-33.
- Rodger, S., & Tooth, L. (2004). "Adult siblings' perceptions of family life and loss: a pilot case study." Journal of Developmental and Physical Disabilities 16(1): 53-71.
- Rodrigue, J. R., Geffken, G.R., & Morgan, S.B. (1993). "Perceived competence and behavioral adjustment of siblings of children with autism." Journal of Autism and Developmental Disorders 23(4): 665-674.
- Roeyers, H., & Mycke, K. (1995). "Siblings of a child with autism, with mental retardation and with a normal development." Child: Care, Health and Development 21(5): 305-319.
- Rogers-Adkinson, D. L., Ochoa, T.A., & Delgado, B. (2003). "Developing cross-cultural competence: serving families of children with significant developmental needs." Focus on Autism and Other Developmental Disabilities 18(1): 4-8.

- Rogoff, B. (1990). Apprenticeship in Thinking: cognitive development in social context. Oxford: Oxford University Press.
- Rogoff, B. (2003). The Cultural Nature of Human Development. NY: Oxford University Press.
- Rose, G. (2001). Visual Methodologies. London: Sage.
- Rosenstein, B. (2002). "Video Use in Social Science Research and Programme Evaluation." Journal of Qualitative Methods 1(3): Article 2.  
<http://www.ualberta.ca/~ijqm> Access date: 15/10/2004
- Ross, N. J. (2005). "Children's space." International Research in Geographical & Environmental Education 14(4): 336-341.
- Ross, P., & Cuskelly, M. (2006). "Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder." Journal of Intellectual & Developmental Disability 31(2): 77-86.
- Rossiter, L., & Sharpe, D. (2001). "The siblings of individuals with mental retardation: a quantitative integration of the Literature." Journal of Child and Family Studies, 10(1): 65-84.
- Rutter, M. (1993). Psychosocial resilience and protective mechanisms. In: J. Rolf, A. Masten, D. Cicchetti, K. Neuchterlein, & S. Weintraub (Eds.), Risk and protective factors in the development of psychopathology. NY: Cambridge University Press. 181-214
- Rutter, M. (1999). "The Emanuel Miller memorial lecture 1998 Autism: two-way interplay between research and clinical work." Journal of Child Psychology and Psychiatry 40(2): 169-188.
- Rutter, M. (2005a). "Aetiology of autism: findings and questions." Journal of Intellectual Disability Research 49(4): 231-238.
- Rutter, M. (2005b). "Incidence of autism: change over time and their meaning." Acta Paediatrica 94(1): 2-15.
- Sacks, H., Schegloff, E.A., & Jefferson, G. (1974). "A Simplest systematics for the organization of turn-taking for conversation." Language 50(4): 696-735.
- Saleebey, D., Ed. (2005). The Strengths Perspective in Social Work Practice. Boston: Allyn & Bacon.
- Salganik, M. J., & Heckathorn, D.D. (2004). "Sampling and estimation in hidden populations using respondent-driven sampling." Sociological Methodology 34(1): 193-239.

- Sanders, J. L., & Morgan, S. B. (1997). "Family stress and adjustment as perceived by caregivers of children with autism or down syndrome: implications for intervention." Child and Family Behaviour Therapy 19(4): 15-32.
- Sanders, R. (2004). Sibling Relationship: theory and issues for practice. NY: Palgrave macmillan.
- Saner E (2007). "'It is not a disease, it is a way of life'". *The Guardian*. <http://society.guardian.co.uk/health/story/0,,2143123,00.html>. Retrieved on 2007-08-07.
- Sarantakos, S. (1998). Social Research. London: Macmillan.
- Schaeffer, J. H. (2003). Videotape: New techniques of observation and analysis in anthropology. In: P. Hockings (Ed.) Principles of Visual Anthropology. NY: Mouton de Gruyter: 255-284.
- Scott, J. K., Wishart, J.G., & Bowyer, D.J., (2006) "Do current consent and confidentiality requirements impede or enhance research with children with learning disabilities?" Disability and Society 21(3) 273-287
- Byrne, B. (2004). Qualitative interviewing. In: Seal, C. (Ed.). Researching Society and Culture. 2<sup>nd</sup> ed. London: Sage. 179-192.
- Seligman, M. (1999). Childhood disability and the family. In: V. L. Schwean, & D. H. Saklofske (Eds.) Handbook of Psychosocial Characteristics of Exceptional Children. NY: Kluwer Academic/Plenum Publishers: 111-132.
- Seligman, M., & Darling, R. B. (1997). Ordinary Families, Special Children: a systems approach to childhood disability. London: the Guilford press.
- Seltzer, M. M., Greenberg, J.S., Orsmond, G.I., & Lounds, J. (2005). "Life course studies of siblings of individuals with developmental disabilities." Mental Retardation 43(5): 354-359.
- Seo, D. M. (2005). Implications for appropriate attitude toward people with disabilities. In: Kim, Y. D. & Yoo, D.C. (Eds.) The Understanding of Welfare for People with Disabilities in Korea. Korea, Seoul: Ingan-gwa-Bokji: 61-86. in Korean
- Seo, H. J. (1994). Children with autism and self-support theory. Korean Academy of Social Work Autumn Conference, Seoul. in Korean
- Seo, H. J. (1999). A Theory of Family Support of Children with Disabilities. Korea, Seoul: Hongikje. in Korean
- Seo, M. H., Lee, S.H., & Lim, Y.K. (2001). Status of Child Care Programs and Improvement Plans for Disabled Children. Seoul: KIHASA. in Korean

- Seo, M. S. (2004). "Factors Influencing the Adjustment of the Siblings of Handicapped Children in School and in the Family." Korean Journal of Home Management 22(6): 201-218. in Korean
- Shah, R., & Hutton, C. (1999). Caring Alone: young carers in South Asian Communities. Ilford: Barnardos.
- Shakespeare, T. (1994). "Cultural representation of disabled people: dustbins for disavowal?" Disability & Society 9(3): 283-299.
- Shakespeare, T. (1999). "'Losing the plot'? medical and activist discourses of contemporary genetics and disability." Sociology of Health & Illness 21(5): 669-688.
- Shakespeare, T. (2005). "Review article: disability studies today and tomorrow." Sociology of Health & Illness 27(1): 138-148.
- Shakespeare, T., & Watson, N. (2001). "The social model of disability: an outdated ideology?" Research in Social Science and Disability 2: 9-28.
- Shakespeare, T., & Watson, N. (1998). Theoretical perspectives on research with disabled children. In: C. Robinson & K. Stalker (Eds.) Growing up with Disability Research. London: Jessica Kingsley: 13-28
- Sharpe, D., & Rossiter, L. (2002). "Siblings of children with a chronic illness: a meta-analysis." Journal of Pediatric Psychology 27(8): 699-710.
- Shim, Y. H. (2001). "Feminism and the discourse of sexuality in Korea: continuities and changes." Human Studies 24(1/2): 133-148.
- Shin, C. S., & Shaw, I. (2003). "Social policy in South Korea: cultural and structural factors in the emergence of welfare." Social Policy and Administration 37(4): 328-341.
- Shin, D. M. (2003). Social and Economic Policies in Korea. London: RoutledgeCurzon.
- Shin, H. J. (1995). The Effects of sibling intervention on the improvement of sociality in autistic children. Tae-Gu University. MA Dissertation. in Korean
- Shin, H. J. (2000). A Study of the Sibling Relationship and Psycho-Social Function on Siblings of Children with Autism. Tae-gu University. Ph.D Thesis. in Korean
- Shin, H. Y. (2002). Study on Problem Behavior and Sibling Relationship of Adolescents without Disability who have Developmentally Disabled Siblings. Yon-Sei Univeristy. MA Dissertation. in Korean
- Shin, J. Y. (2002). "Social support for families of children with mental retardation: comparison between Korean and the United States." Mental Retardation 40(2): 103-118.

- Shin, J. Y., Seo, E.J., & Lee, S.B. (2004). "The Comparative study between Korea and the United States on social supports for families of children with developmental disabilities." Journal of Emotional & Behavioral Disorders 20(3): 127-158.
- Shudy, M., de Almeida, M, L., Ly, S., Landon, C., Groft, S., Jenkins, T.L. & Nicholson, C.E. (2006). "Impact of Pediatric Critical Illness and Injury on Families: A Systematic Literature Review." Pediatrics 118(3): s203-s218.
- Shuwa, A., Fitzgerald, B., & Clemente, C. (2006). "Children with learning disabilities and related needs placed out of borough: parents' perspective." Psychiatric Bulletin 30(3): 100-102.
- Sidhu, R., Passmore, A., & Baker, D. (2005). "An investigation into parent perceptions of the needs of siblings of children with cancer." Journal of Pediatric Oncology Nursing, 22(5): 276-287.
- Siegel, B., & Silverstein, S. (1994). What about me? Growing up with a developmentally disabled sibling. NY: Insight Books.
- Siegel, B. (1996). The World of the Autistic Child. Oxford: Oxford University Press.
- Silver, E. J., & Frohlinger-Graham, M.J. (2000). "Brief report: psychological symptoms in healthy female siblings of adolescents with and without chronic conditions." Journal of Pediatric Psychology, 25(4): 279-284.
- Simeonsson, R. J., & McHale, S. M. (1981). "Review: Research on handicapped children: sibling relationship." Child: Care, Health and Development 7(3): 153-171.
- Sinclair, R. (2004). "Participation in practice: making it meaningful, effective and sustainable." Children and Society 18(2): 106-118.
- Sivberg, B. (2002). "Family system and coping behaviors: a comparison between parents of children with autistic spectrum disorders and parents with non-autistic children." Autism 6(4): 397-409.
- Sloper, P. (2000). "Experiences and support needs of siblings of children with cancer." Health and Social Care in the Community 8(5): 298-306.
- Sloper, P., & While, D. (1996). "Risk factors in the adjustment of siblings of children with cancer." Journal of Child Psychology & Psychiatry 37(5): 597-607.
- Smith, C. (1997). "Children's rights: have carers abandoned values?" Children & Society 11(1): 3-15.
- Smith, C. (2007) Children's rights and early childhood education: links to theory and advocacy. Australian Journal of Early Childhood 32(3)  
[http://www.earlychildhoodaustralia.org.au/australian\\_journal\\_of\\_early\\_childhood/ajec\\_index\\_abstracts/childrens\\_rights\\_and\\_early\\_childhood\\_education.html](http://www.earlychildhoodaustralia.org.au/australian_journal_of_early_childhood/ajec_index_abstracts/childrens_rights_and_early_childhood_education.html) Access date: 21/2/2008

- Smith, G. C., Hatfield, A. B., & Miller, D. C. (2000). "Planning by older mothers for the future care of offspring with serious mental illness." Psychiatric Services, 51(9): 1162-1166.
- Smith, T. (2006) "Outcome of Early Intervention for Children With Autism." Clinical Psychology: Science and Practice 6(1) 33 - 49
- Smith, T., & Perry, A. (2004). "A sibling support group for brothers and sisters of children with autism." Journal on Developmental Disabilities 11(1): 77-88.
- Snyder, S. L., & Mitchell, D.T. (2006). Cultural Locations of Disability. Chicago: The University of Chicago Press.
- The Son-Rise Program <http://www.autismtreatmentcenter.org/>
- Spiers, J. A. (2004) Tech tips: Using video management/ analysis technology in qualitative research. International Journal of Qualitative Methods, 3(1) [http://www.ualberta.ca/~iiqm/backissues/3\\_1/pdf/spiersvideo.pdf](http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/spiersvideo.pdf) Access date: 2/2/2008
- Spreen, M., & Zwaagstra, R. (1994). "Personal network sampling, outdegree analysis and multi level analysis: introducing the network concept in studies of hidden populations." International Sociology 9(4): 475-491.
- Stalker, K. (1998) "Some ethical and methodological issues in research with people with learning disabilities." Disability and Society, 13 (1). 5-19.
- Stalker, K. (2003). Carers: an overview of concepts, developments and debates. In: K. Stalker (Ed.) Reconceptualising Work with 'Carers': new directions for policy and practice. London: Jessica Kingsley Publishers: 15-36.
- Standard Korean Language Dictionary (1999) <http://www.sejong.or.kr/>
- Stanton, M. (2000). Learning to live with high functioning autism: a parent's guide for professionals. London: Jessica Kingsley Publishers.
- Stanton-Salazar, R.D., & Spina, S.U. (2000). "The Network orientations of highly resilient urban minority youth: a network-analytic account of minority socialization and its educational implications. The Urban Review. 32(3) 227-261.
- Stawski, M., Auerbach, J.G., Barasch, M., Lerner, Y., & Zimin, R. (1997). "Behavioural problems of children with chronic physical illness and their siblings." European Child & Adolescent Psychiatry 6(1): 20-25.
- Stocker, C. M., & McHale, S. M. (1992). "The nature and family correlates of preadolescents' perceptions of their sibling relationships." Journal of Social and Personal Relationships 9(2): 179-195.

Stoneman, Z. (1998). Research on siblings of children with mental retardation: contributions of developmental theory and etiology. In: A. B. Jacob, R. M. Hodapp, & E. F. Zigler (Eds.) Handbook of Mental Retardation and Development. Cambridge: Cambridge University Press: 669-692.

Stoneman, Z. (2001). "Supporting positive sibling relationships during childhood." Mental Retardation & Developmental Disabilities Research Reviews 7(2): 134-142.

Stoneman, Z. (2005). "Siblings of children with disabilities: research themes." Mental Retardation 43(5): 339-350.

Stoneman, Z., & Brody, G. H. (1993). Sibling relations in the family context. In: Z. Stoneman, & P.W. Berman (Eds.) The effects of mental retardation, disability, and illness on sibling relationships: research issues and challenges. Baltimore: Paul H. Brookes.: 3-30.

Stoneman, Z., Brody, G. H., Davis, C. H., & Crapps, J. (1988). "Childcare responsibilities, peer relations, and sibling conflict: older siblings of mentally retarded children." American Journal on Mental Retardation 93(2): 174-183.

Strauss, A., & Corbin, J. (1998). Basics of Qualitative Research: grounded theory procedures and techniques. London: Sage.

Strohm, K. E. (2002). Siblings: Brothers and sisters of children with special needs. Adelaide: Wakefield press.

Suaalii, T. M., & Mavoa, H. (2001). "Who says yes? Collective and individual framing of Pacific children's consent to, and participation in, research in New Zealand." Childrenz Issues 5(1): 39-42.

Suchar, C. S. (1997). "Grounding visual sociology research in shooting scripts." Qualitative Sociology 20(1): 33-55.

Sung, C. H., Yeo, J.Y., Woo, G.H., & Choi, S.H. (2005). Social Work with Families. Korea, Seoul: Yangseowon. In Korean

Sung, K.T. (1996) "Comparison of motivations for parent care between Koreans and Americans: a cross-cultural approach." Korea Journal of Population and Development. 25(1) 83- 99

Sung, K. T. (1998a). "Filial Piety: the traditional ideal of parent care in East Asia." Retrieved 29. 5, 2007, from <http://www.asaging.org/networks/forsa/a&s-101.html>.

Sung, K. T. (1998b). "An Exploration of actions of filial piety." Journal of Aging Studies 12(4): 369-386.

Sung, S. R. (2003). "Women reconciling paid and unpaid work in a Confucian welfare state: the case of South Korea." Social Policy & Administration 37(4): 342-360.



Suzuki, L. K., & Greenfield, P.M. (2002). "The Construction of everyday sacrifice in Asian Americans and European Americans: the roles of ethnicity and acculturation." Cross-Cultural Research 36(3): 200-228.

Swain, J., & French, S. (2000). "Towards an affirmation model of disability." Disability & Society 15(4): 569-582.

Swain, J., French, S., Barnes, C., & Thomas, C., (Ed.) (2004). Disabling Barriers-Enabling Society. London: Sage.

Swain, J., French, S., Cameron, C. (2003). Controversial Issues in a Disabling Society. Buckingham: Open University Press.

Tak, Y. R., & McCubbin, M. (2002). "Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease." Journal of Advanced Nursing, 39(2): 190-198.

Tamai, K., & Lee, J.H. (2002). "Confucianism as cultural constraint: a comparison of Confucian values of Japanese and Korean university students." International Education Journal 3(5): 33-49.

Tao, J., & Drover, G. (1997). "Chinese and Western Notions of Need." Critical Social Policy 17(50): 5-25.

Taskinen, S. (2003). The family as health-care agent: a psychological perspective. The family in the health system: a cost-raising or cost-reducing factor? European Observatory on the Social Situation, Demography and Family, Tutzing, Germany.

Taylor, V., Fuggle, P., & Charman, T. (2001). "Well sibling psychological adjustment to chronic physical disorder in a sibling: how important is maternal awareness of their illness attitudes and perceptions?" Journal of Child Psychology and Psychiatry 42(7): 953-962.

Tharpe, R. G., & Gallimore, R. (1988). Rousing Minds to Life. Cambridge, Cambridge University Press.

The Child Care Act (revised 2001). <http://www.klaw.go.kr/> in Korean

The Child Welfare Act (amended 2000) <http://www.klaw.go.kr/> in Korean

The Child Welfare Act (revised 2001). <http://www.klaw.go.kr/> in Korean

The Convenience Promotion Law for the Disabled, the Elderly and Pregnant Women 1997. <http://www.klaw.go.kr/> in Korean

The Disability Discrimination Act 2007. <http://www.klaw.go.kr/> in Korean

The National Basic Livelihood Security Act. <http://www.klaw.go.kr/> in Korean

- The Promotion of Special Education (amended 2001). <http://www.klaw.go.kr/> in Korean
- The Promotion of the Employment of People with Disabilities (amended 2001). <http://www.klaw.go.kr/> in Korean
- The Special Education Act for Children with Special Needs' 2007. <http://www.klaw.go.kr/> in Korean
- Thomas, C. (2004). Disability and impairment. In: J. Swain, S. French, C. Barnes, & C. Thomas (Eds.) Disabling Barriers–Enabling Environments. London: Sage: 21-27.
- Thomas, K. (2006). "The 'Nature' of childhood: ethnography as a tool in approaching children in archaeology." Archeological Papers of the American Anthropological Association 15(1): 41-50.
- Thomas, N., & O'Kane, C. (1998). "The Ethics of participatory research with children." Children & Society 12(5): 336-348.
- Thomas, N., Stainton, T., Jackson, S., Cheung, W.Y., Doubtfire, S., & Webb, A. (2003). "'Your friends don't understand': invisibility and unmet needs in the lives of 'young carers'." Child & Family Social Work 8(1): 35-46.
- Thorne, B. (1993). Gender Play: girls and boys in school. Buckingham: Open University Press.
- Titchkosky, T. (2003). Disability, Self, and Society. Toronto: University of Toronto Press.
- Tozer, R. (1996). "My brother's keeper? sustaining sibling support." Health and Social Care in the Community 4(3): 177-181.
- Tregaskis, C. (2002). "Social model theory: the story so far..." Disability & Society 17(4): 457-470.
- Trevarthen, C., Aitken, K., Papoudi, D., & Robarts, J. (1998). Children with Autism: diagnosis and interventions to meet their needs. London: Jessica Kingsley.
- Triandis, H.C. (1995). Individualism & Collectivism. Oxford: Westview Press
- Trute, B., & Hiebert-Murphy, D. (2002). "Family adjustment to childhood developmental disability: a measure of parent appraisal of family impacts." Journal of Pediatric Psychology 27(3): 271-280.
- Tucker, F., & Matthews, H. (2001). "'They don't like girls hanging around there': conflicts over recreational space in rural Northamptonshire." Area 33(2): 161-168.
- Underdown, A. (2002). "I'm growing up too fast': messages from young carers." Children & Society 16(1): 57-60.

- Ungar, M. (2008) "Resilience across cultures." The British Journal of Social Work 38(2): 218-235
- Unicef (2007) Every Child Matters: The five Outcomes and the UN Convention on the Rights of the Child (UNCRC).  
<http://www.everychildmatters.gov.uk/files/F1B3FBF728B196018E9616C71D0BF592.pdf>. Access date: 13/3/2009
- United Nations (1989). United nations convention on the rights of the child. Geneva: United Nations.
- van den Hoed-Heerschop, C. (2007). "Commentary on "Experience of siblings of children treated for cancer"." European Journal of Oncology Nursing 11(2): 113-114.
- Van Lange, P. A. M., Agnew, C.R., Harinck, F., & Steemers, G.E.M. (1997). "From game theory to real life: how social value orientation affects willingness to sacrifice in ongoing close relationships." Journal of Personality and Social Psychology 73(6): 1330-1344.
- Van Riper, M. (2000). "Family variables associated with well-being in siblings of children with Down syndrome." Journal of Family Nursing 6(3): 267-286.
- Van Riper, M. (2003). The Sibling experiences of living with childhood chronic illness and disability. In: M. S. Miles, & D. Holditch-Davis (Eds.) Annual Review of Nursing Research. Vol.21. NY: Springer. 279-302.
- Veale, A. (2005). Creative methodologies in participatory research with children. In: S. Greene, & D. Hogan (Eds.) Researching Children's Experience: approaches and methods. London: Sage: 253-272.
- Ventres, W., Kooienga, S., Vuckovic, N., Marlin, R., Nygren, P., & Stewart, V. (2006). "Physicians, patients, and the electronic health record: an ethnographic analysis." Annals of Family Medicine 4(2): 124-131.
- Verté, S., Roeyers, H., & Buysse, A. (2003). "Behavioural problems, social competence and self-concept in siblings of children with autism." Child: Care, Health & Development 29(3): 193-205.
- Vidich, A. J., & Lyman, S.M. (2000). Qualitative methods: their history in sociology and anthropology. In: N.K. Denzin & Y.S. Lincoln (Eds.) Handbook of Qualitative Research. Thousand Oaks, CA: Sage: 37-84.
- Volling, B. L. (2003). Sibling relationships. In: M. H. Bornstein, L. Davidson, C.L.M. Keyes, & K. Moore (Eds.) Well-being: positive development across the life course. Mahwah, NJ: Lawrence Erlbaum Associates: 205-220.

- Volling, B. L. (2005). "The transition to siblinghood: a developmental ecological systems perspective and directions for future research." Journal of Family Psychology 19(4): 542-549.
- Vygotsky, L. (1962). Thought and language. Massachusetts, Cambridge: the MIT press.
- Vygotsky, L. (1993). The Collected Works of L.S.Vygotsky. Vol.2: The fundamentals of defectology (abnormal psychology and learning disabilities). New York: Plenum Press.
- Wall, S. (2006). "An Autoethnography on learning about autoethnography." International Journal of Qualitative Methods 5(2).  
[http://www.ualberta.ca/~iiqm/backissues/5\\_2/pdf/wall.pdf](http://www.ualberta.ca/~iiqm/backissues/5_2/pdf/wall.pdf) Access date: 12/6/2006
- Walsh, D. J., Bakir, N., Tony, B.L., Chung, Y-H., Chung, K., & Colleagues. (2007). Using digital video in field-based research with children. In: J. A. Hatch (Ed.) Early Childhood Qualitative Research. NY: Routledge: 43-62.
- Waltz, M. (2005). "Reading case studies of people with autistic spectrum disorders: a cultural studies approach to issues of disability representation." Disability & Society 20(4): 421-435.
- Wang, R. H., & Martinson, I.M. (1996). "Behavioral responses of healthy Chinese siblings to the stress of childhood cancer in the family: a longitudinal study." Journal of Pediatric Nursing, 11(6): 383-391.
- Warren, J. (2007). "Young carers: conventional or exaggerated levels of involvement in domestic and caring tasks?" Children & Society 21(2): 136-146.
- Watson, N. (2002). "Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: identity and disability." Disability & Society 17(5): 509-527.
- Weisner, T. (2002). " Ecocultural understanding of children's developmental pathways." Human Development 45(4): 275-281.
- Weisner, T. S. (1993a). Ethnographic and ecocultural perspectives on sibling relationships. In: Z. Stoneman & P.W. Berman (Eds.) The Effects of Mental Retardation, Disability, and Illness on Sibling Relationships. Baltimore: Brookes: 51-83.
- Weisner, T. S. (1993b). Overview: siblings similarity and difference in different cultures. In: C. W. Nuckolls (Ed.) Siblings in South Asia: brothers and sisters in cultural context. London: the Guilford Press: 1-18.
- Welfare Coordination Committee for Disabled Persons. (2003). "The 2nd Welfare Development Plan for Disabled Persons." Retrieved 30 April, 2007, [http://mohw.go.kr/user.tdf?a=user.tbdata.BoardApp&c=2002&seq=31752&board\\_id=g\\_p\\_tb\\_data&mc=P\\_02\\_02\\_02&bunr\\_code=130&skin=p\\_new\\_m2\\_common&scd\\_day=](http://mohw.go.kr/user.tdf?a=user.tbdata.BoardApp&c=2002&seq=31752&board_id=g_p_tb_data&mc=P_02_02_02&bunr_code=130&skin=p_new_m2_common&scd_day=) in Korean

- The Welfare law for Mentally and Physically Handicapped 1981. <http://www.klaw.go.kr/> in Korean
- The Welfare of Disabled Persons Act 1989. <http://www.klaw.go.kr/> in Korean
- The Welfare of Disabled Persons Act (amended 1999). <http://www.klaw.go.kr/> in Korean
- Tseng, W. S. (1973). "The Concept of personality in Confucian thought." *Psychiatry*. 36. 191-202.
- Welterlin, A., & LaRue, R.H. (2007). "Serving the needs of immigrant families of children with autism." *Disability & Society* 22(7): 747-760.
- Whitaker, P. (2002). "Supporting families of preschool children with autism: what parents want and what helps." *Autism* 6(4): 411-426.
- Whyte, S. R., & Ingstad, B. (1995). Disability and culture: an overview. In: B. Ingstad, & S.R. Whyte (Eds.) *Disability and Culture*. London: University of California Press: 3-32.
- Wiles, R., Heath, S., Crow, G., & Charles, V. (2005). Informed Consent in Social Research: a literature review, ESRC National Centre for Research Methods. <http://www.ncrm.ac.uk/research/outputs/publications/methodsreview/MethodsReviewPaperNCRM-001.pdf>. Access date: 30/1/2008
- Wilkins, K. L., & Woodgate, R.L. (2007). "An Interruption in family life: siblings' lived experiences as they transition through the pediatric Bone Marrow Transplant Trajectory." *Oncology Nursing Forum*(34): 2. <http://www.ons.org/Publications/journals/ONF/volume34/issue2/3402311.asp> Access date:23/2/2008
- Williams, J., & Brayne, C. (2006). "Screening for autism spectrum disorders." *Autism* 10(1): 11-35.
- Williams, P. D. (1997). "Siblings and pediatric chronic illness: a review of the literature." *International Journal of Nursing Studies* 34(4): 312-323.
- Williams, P. D., Williams, A., Hanson S., Graff, C., Ridder, L., Curry, H., Liebergen, A., & Karlin-Setter, R. (1999). "Maternal mood, family functioning, and perceptions of social support, self-esteem, and mood among siblings of chronically ill children." *Children's Health Care* 28(4): 297-310.
- Williams, J.H.G., Waiter G.D., Gilchrist, A., Perrett, D.I., Murray, A.D., & Whiten, A. (2006) "Neural mechanisms of imitation and 'mirror neuron' functioning in autistic spectrum disorder." *Neuropsychologia* 44(4) 610-621.

- Wilson, J. (1989). "Siblings of Children with Severe Handicaps." Mental Retardation 27(3): 167-173.
- Winton, C.A. (2003) Children as Caregivers: Parental and parentified children. Boston: Allyn and Bacon.
- Wolf, L., Fisman, S. Ellison D., & Freeman, T. (1998). "Effect of sibling perception of differential parental treatment in sibling dyads With one disabled child." Journal of the American Academy of Child and Adolescent Psychiatry 37(12): 1317-1325.
- Won, J. W., Krajicek, M., & Lee, H.O. (2004). "Culturally and linguistically competent care of a Korean-American child with autism." Illness, Crisis & Loss 12(2): 139-154.
- Won, S. Y., & Pascall, G. (2004). "A Confucian war over childcare? practice and policy in childcare and their implications for understanding the Korean gender regime." Social Policy and Administration 38(3): 270-289.
- Woodhead, M. (1997). Psychology and the cultural construction of children's needs. In: A. James, & A. Prout (Eds.) Constructing and Reconstructing Childhood: contemporary issues in the sociological study of childhood. London, Falmer Press: 63-84.
- Woodhead, M., & Faulkner, D. (2000). Subjects, objects or participants? Dilemmas of psychological research with children. In: P. Christensen & A. James (Eds.) Research with Children: perspectives and practices. London: Falmer Press: 9-35.
- Wong, G. (2004) Resilience in Asian context. In: C. S. Clauss-Ehlers, & M. D. Weist (Eds.) Community Planning to Foster Resilience in Children. NY: Springer. 99-112.
- World Health Organization (WHO). (2003). "International Statistical Classification of Diseases and Related Health Problems -10th Revision." Retrieved 28th. July, 2006, from <http://www.who.int/classifications/apps/icd/icd10online2003/fr-icd.htm>.
- Worth, S., & Adair, J. (1972). Through Navajo Eyes: an exploration in film communication and anthropology. Bloomington: Indiana University Press.
- Wyness, M. (2000). Contesting Childhood. London: Falmer.
- Yang, C. K., & Hahn, H.M. (2002). "Cosleeping in young Korean children." Journal of Developmental and Behavioral Pediatrics 23(3): 151-157.
- Yang, I. J. (2006). "Jeong exchange and collective leadership in Korean organization." Asia Pacific Journal of Manage 23(3): 283-298.
- Yang, O. K. (2001). "Study on college students' perception of family." Journal of Korean Family Social work 7: 175-199. in Korean
- Yang, O.K., & Choi, M.M. (2001) "Koreans' Han and resilience: applications to mental health social work." Mental Health & Social Work. 11(6) 7-29 In Korean

- Yang, S. E., & Retting, K. D. (2003). "The Value tensions in Korean-American mother-child relationships while facilitating academic success." Personal Relationships 10(3): 349-369.
- Yang, S. G., & Rosenblatt, P.C. (2008). "Confucian family values and childless couples in South Korea." Journal of Family Issues 29(5): 571-591.
- Yang, S. M. (2003). "The Review of support program for the non-handicapped persons with th handicapped siblings." Korean Journal of Family Welfare 8(1): 69-84. in Korean
- Yang, S.N. (2008) "Cane of love: parental attitudes towards corporal punishment in Korea." British Journal of Social Work. *Online Early View*
- Yao, X. (2000) An Introduction to Confucianism. Cambridge: Cambridge University Press
- Yeh, K. H. (2003). The beneficial and harmful effects of filial piety: An integrative analysis. In: K. S. Yang, K. K. Hwang, P. B. Pederson & I. Daibo (Eds.) Asian Social Psychology: Conceptual and Empirical Contributions. Connecticut: Greenwood Publishing. 67-82
- Yim, H. S. (2002). "Cultural identity and cultural policy in South Korea." The International Journal of Cultural Policy 8(1): 37-48.
- Yirimiya, N., Shaked, M., & Erel, O. (2001). Comparison of siblings of individuals with autism and siblings of individuals with other diagnoses: An empirical summary. In: E. Schopler, N. Yirimiya, C. Shulman, & L. M. Marcus (Eds.) The Research Basis for Autism Intervention. NY: Kluwer Academic/Plenum Publishers.: 59-73.
- Yoo, D. C. (2004). The outcomes and tasks of disability movement. 2004 Korea Disabled Leaderships Forum, Seoul, Korea Differently Abled Federation. in Korean
- Yoo, D. C. (2005). The outcomes and tasks of Korea disability movement. In: Kim, Y. D. & Yoo, D.C. (Eds.) A Understanding of Welfare for People with Disabilities in Korea. Seoul, Human & Welfare: 497-545. in Korean
- Yoo, H. J. (2005). Current problems of disability registration system and implications: through Cerebral palsy people's perspectives. Public Forum for Implication of Disability Registration system. Seoul: Korea United Cerebral Palsy: 7-26. in Korean
- Yoon, C. Y. (2002). The Children Welfare Act. In: Park, C.N., Shim, H.K.,N., Yoon, C.Y.,& Lee, C.J. (Eds.) The Report of Investigation regarding Infrigement of Legislations of Children, Youth Rights. Korea, Seoul: National Human Rights Commission of Korea: 1-34. in Korean
- Yoon, J. R., Won, J.R., Kwon, H.S., Yoo, J.S., & Kim, J.Y. (2005). Status Survey on Inclusive Education for School-Aged Disabled Children. Korea, National Human Rigths Commission of Korea: National Human Rigths Commission of Korea. in Korean

- Yoon, S. Y. (2002). "Welfare for disabled people: progress assessment and future direction." Policy Forum 65. in Korean
- Yoon, S. Y. (2007). "Implication of the change in disability benefit system in 2007 and long-term improvement plan." Welfare Forum 127: 41-54. in Korean
- Yoshida, K. K., & Odette, F. (1999). "Cross-cultural views of disability and sexuality: experiences of a group of ethno-racial women with physical disabilities." Sexuality and Disability 17(4): 321-337.
- You, H. K. (2002). A Study on the Sibling Support Programs for Disabled Children. Dan-Kook University. MA Dissertation. in Korean
- Youn, G. H., Knight, B.G., Jeong, H.S., & Benton, D. (1999). "Differences in familism values and caregiving outcomes among Korean, Korean American, and White American dementia caregivers." Psychology & Aging 14(3): 355-364.
- Youn, J. S. (2007). Survey on current therapeutic educational services and implications for policy: through parental opinions. Forum of Therapeutic Education and Support Services for Disabled Children. Korea, Seoul: Jange ai we-can/ The Joint Association of the Education Rights for the Disabled. in Korean
- Young, L., & Barrett, H. (2001). "Adapting visual methods: action research with Kampala street children." Area 33(2): 141-152.
- Yu, D. S. F., Lee, D.T.F., & Woo, J. (2003). "Translation of the chronic heart failure questionnaire." Applied Nursing Research 16(4): 278-283.
- Zhou, M. & Bankston, C. L. (1998). Growing Up American: How Vietnamese Children Adapt to Life in the United States. NY: Russell Sage Foundation.



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## **Appendices**

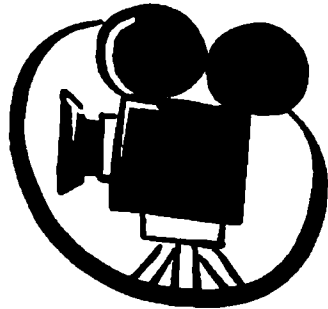
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## Appendix-A Information Package



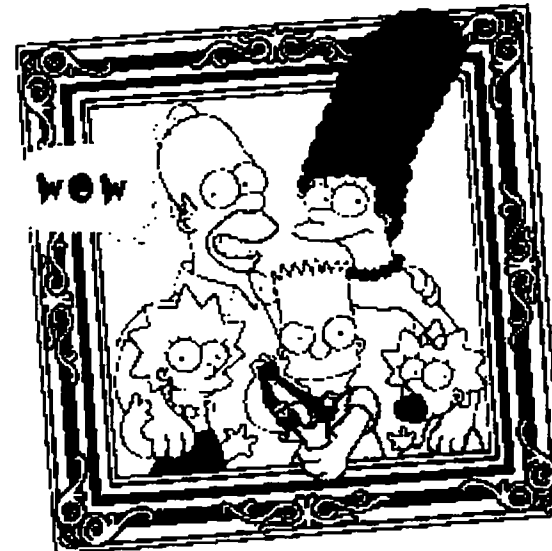
**For Further Enquiries  
Contact (Korea):**

황 세 광  
Phone: 032) 000-000  
Mobile: 0191-000-0000



## My Family My life

(INFORMATION LEAFLET FOR CHILDREN)



**Contact (UK) :**

SE-KWANG, HWANG  
University of Durham  
Centre for Applied Social Studies  
Elvet Riverside 2  
New Elvet  
Durham  
DH1 3JT  
Telephone: 44-191-3341476  
E-mail: [s.k.hwang@durham.ac.uk](mailto:s.k.hwang@durham.ac.uk)



Hi!

My name is Se Kwang, Hwang  
I am presently studying for a Doctoral degree in Social Work at  
Durham University, England.

This leaflet is about a researching your everyday life with your  
autistic brother or sister.  
So, , I'd like to show you how you can have fun.



- 396 -  
You will make video diaries and a  
family movie using a hypermedia gadget for  
two weeks. It can be a fantastic experience.  
I'd also like to hear your videos



We can also have time to talk and play,  
if you like.



Do you want to be in this project?  
If you do, I will come and see you and your family at home.

Please read carefully the Agreement Form and write your name at  
the foot of the form, if you would like to join in this project.  
If you don't want to be in the project, it is your choice, and you can  
always change your mind later.

My Family  
My Life



Agreement Form

I have read the leaflet

or

The leaflet has been read to me  
I would like to take part in the research  
I agree to audio/video recording of my information and participation.  
I know that while any information will be presented, I will not be  
identified, and my information will remain secret.  
I know I can leave at any time if I don't want to continue.  
I know that without my agreement the video recording cannot be  
used for any other purposes in the future.

Child' Name \_\_\_\_\_

Signed on behalf of Child \_\_\_\_\_

Please send this sheet back to me in the envelope provided.

Big Thanks!!

**For Further Enquiries  
Contact (Korea):**

황 세 광  
Phone: 032) 000-000  
Mobile: 0191-000-0000



**INFORMATION LEAFLET FOR TEENS**

## My Family My Life



open house

-397-  
**Contact (UK) :**

SE-KWANG, HWANG  
University of Durham  
Centre for Applied Social Studies  
Elvet Riverside 2  
New Elvet  
Durham  
DH1 3JT  
Telephone: 44-191-3341476  
E-mail: s.k.hwang@durham.ac.uk

Hello!

My name is Se Kwang, Hwang.

I am presently studying for a Doctoral degree in Social Work at Durham University.

This leaflet is about a researching what your life is like living with an autistic borther or sister.

In this project, you will make a video diaries and family movies by using hypermedia gadget for two weeks. It can be be a fantastic experience. I'd also like to hear your views about your videos.

- 398 -  
I hope the project will help you and your family.

Do you want to be in this project?  
If you do, I will come and see you and your family at home.

I would like to talk with you. I won't tell your parents what you said.

You can ask me questions any time freely!

Please read carefully the Agreement Form and write your name at the foot of the form, if you would like to join in this project.

If you don't want to be in the project, it is your choice, and you can always change your mind later.

Thank your for reading this

My Family  
My Life



Agreement Form

I have read the leaflet

And

I would like to take part in the research  
I understand I can leave at any time if I don't want to continue.  
I agree to audio/video recording of my information and participation.  
I know that while any information will be presented, I will not be identified, and my information will remain confidential.  
I know also that without my agreement the video recording during the study cannot be used for any other purposes in the future.

Child' Name \_\_\_\_\_

SING \_\_\_\_\_

or

Signed on behalf of Child \_\_\_\_\_

Please send this sheet back to me in the envelope provided.

Big Thanks for your help.

This research cannot do without your help!

**Contact  
Korea:**

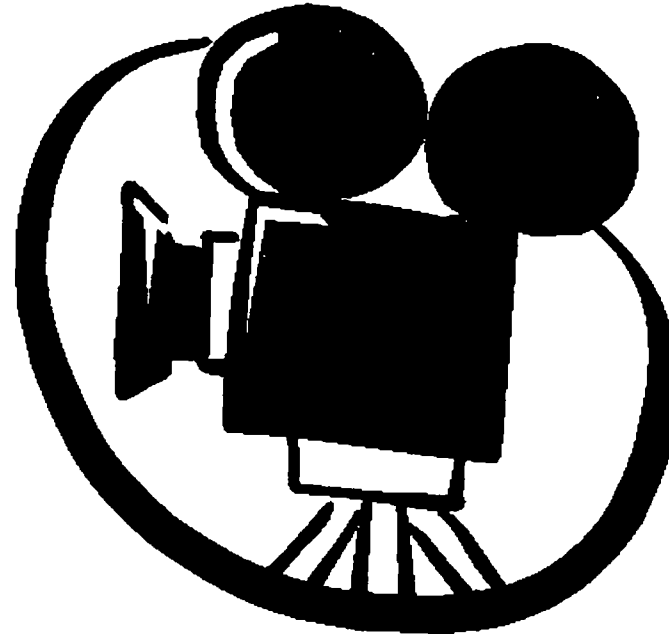
황 세 광  
전화: 032) 862-8438  
핸드폰: 0191-401-8438

Doctoral Study Project:  
*My Family, My Life*

Schedule for  
participation

- 399 -  
**Contact (UK):**

SE-KWANG, HWANG  
University of Durham  
Centre for Applied Social Studies  
Elvet Riverside 2  
New Elvet  
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E-mail: [s.k.hwang@durham.ac.uk](mailto:s.k.hwang@durham.ac.uk)





### Visit-1

During this first visit, I will explain the purpose of the project and topics to be covered.

I will discuss the idea of making videos and the best time for you to make one, if you agree. It is very important that everyone in the family knows what it going on and agrees to take part. I will ask you to look at some forms which explain how the project will be confidential. You should only sign them if, and when, you are happy.

It is essential that you and your family are at home when I visit so that I can show you how to use the PMP. We will try it out together. This should be a lot of fun.



If everyone is still happy with the project, I will lend you the equipment for two weeks so that you can make the movie. I will phone you during the weeks to see how you are getting on, if you agree. But if there are any problems, please phone me straight away.

When the two weeks are up, I will come and collect the camera. If there is anything you want to tell me at that time please say.

I will take the camera away and look at the movie carefully. I am sure that I will have lots of questions about what I see.



### Visit-2

So, after another week or so, I'd like to come watch the movie with you, separate from your other family. I will stop the movie in some places to ask what's going on. If it's OK with you, I will record my questions and your answers on a recorder so that I don't lose your comments. All your videos will be returned to you.

If you like, you will have fun (e.g. writing, drawing, or playing with puppet) during the discussion.



### Visit-3 (for parents)

I would like to ask you questions as parent or parents. These are about your children in everyday life. Please remember that you don't have to answer any questions if you don't want to, and that you can stop the interview at any time without giving a reason. The interview will take about one and half hour. I will record the interview.

Thank you very much indeed for joining this project

## Appendix-B Field Research Time Schedule

	Time duration	Date	Action
Family 1 (Case 1)	28 <sup>th</sup> Aug – 18 <sup>th</sup> Sep	27 <sup>th</sup> Aug	First Contact
		28 <sup>th</sup> Aug	First Meeting
		31 <sup>st</sup> Aug, 4 <sup>th</sup> , 10 <sup>th</sup> , 11 <sup>th</sup> Sep	Progress Check
		18 <sup>th</sup> Sep	Reviewing Session
		18 <sup>th</sup> Sep	Interview (both parents)
Family 2 (Case 2)	23 <sup>rd</sup> Aug – 1 <sup>st</sup> Nov	23 <sup>rd</sup> Aug	First Meeting
		2 <sup>nd</sup> , 5 <sup>th</sup> , 8 <sup>th</sup> Sep	Progress Check
		12 <sup>th</sup> Sep	Second Meeting (failed)
		21 <sup>st</sup> Sep	Interview (mother)
		28 <sup>th</sup> Sep	Third Meeting (failed)
		30 <sup>th</sup> Sep	Fourth Check
		17 <sup>th</sup> Oct	Fourth Meeting (failed)
		1 <sup>st</sup> Nov	Reviewing Session
Family 3 (Case 3)	30 <sup>th</sup> Aug – 13 <sup>th</sup> Oct	30 <sup>th</sup> Aug	First Meeting
		26 <sup>th</sup> Sep	Second Meeting
		28 <sup>th</sup> Sep, 1 <sup>st</sup> , 2 <sup>nd</sup> , 4 <sup>th</sup> , 6 <sup>th</sup> Oct	Progress Check
		8 <sup>th</sup> Oct	Third Meeting
		13 <sup>th</sup> Oct	Reviewing Session
		13 <sup>th</sup> Oct	Interview (mother)
Family 4 (Case 4)	1 <sup>st</sup> Sep – 18 <sup>th</sup> Oct	1 <sup>st</sup> Sep	First Meeting
		20 <sup>th</sup> Sep	Second Meeting
		23 <sup>rd</sup> Sep	Progress Check
		23 <sup>rd</sup> Sep	Third Meeting (repairing job)
		26 <sup>th</sup> , 30 <sup>th</sup> Sep, 4 <sup>th</sup> Oct	Progress Check
		10 <sup>th</sup> Oct	Forth Meeting (failed reviewing session)
		14 <sup>th</sup> Oct	1 <sup>st</sup> Reviewing Session
		15 <sup>th</sup> Oct	2 <sup>nd</sup> Reviewing session
		18 <sup>th</sup> Oct	Interview (mother)
		Family 5 (Case 5)	1 <sup>st</sup> Sep – 26 <sup>th</sup> Oct
5 <sup>th</sup> Oct	Second Meeting		
8 <sup>th</sup> , 11 <sup>th</sup> , 14 <sup>th</sup> , 18 <sup>th</sup> Oct	Progress Check		
19 <sup>th</sup> Oct	Third Meeting		
24 <sup>th</sup> Oct	Reviewing Session		



		26 <sup>th</sup> Oct	Interview (mother)
Family 6 (Case 6)	2 <sup>nd</sup> Sep – 16 <sup>th</sup> Nov	2 <sup>nd</sup> Sep	Initial Contact
		8 <sup>th</sup> Sep	First Meeting
		25 <sup>th</sup> Oct	Second Meeting
		28 <sup>th</sup> Oct, 1 <sup>st</sup> , 5 <sup>th</sup> , 7 <sup>th</sup> Nov	Progress Check
		8 <sup>th</sup> Nov	Third Meeting
		15 <sup>th</sup> Nov	Reviewing Session
		16 <sup>th</sup> Nov	Interview (mother)
		Family 7	6 <sup>th</sup> Sep – 5 <sup>th</sup> Nov
13 <sup>th</sup> Sep	Cancelled because of mother's illness & operation		
Family 8	6 <sup>th</sup> Sep – 3 <sup>rd</sup> Nov	6 <sup>th</sup> Sep	First Meeting
		20 <sup>th</sup> Oct	Second Meeting
		24 <sup>th</sup> , 27 <sup>th</sup> Oct, 1 <sup>st</sup> Nov	Progress Check
		3 <sup>rd</sup> Nov	Second Meeting (Accident)
		10 <sup>th</sup> Nov	Third Meeting (failed)
	11 <sup>th</sup> Nov	Fourth Meeting (failed, cancelled joining because of father's serious injury)	
Family 9 (Case 7)	15 <sup>th</sup> Sep – 29 <sup>th</sup> Nov	15 <sup>th</sup> Sep	First Meeting
		4 <sup>th</sup> Nov	Second Meeting
		7 <sup>th</sup> , 10 <sup>th</sup> , 13 <sup>th</sup> , 16 <sup>th</sup> Nov	Progress Check
		18 <sup>th</sup> Nov	Third Meeting
		27 <sup>th</sup> Nov	Reviewing Session
		29 <sup>th</sup> Nov	Interview (mother)
Family 10 (Case 8)	28 <sup>th</sup> Oct – 21 <sup>st</sup> Nov	28 <sup>th</sup> Oct	First Meeting
		31 <sup>st</sup> Oct, 3 <sup>rd</sup> , 7 <sup>th</sup> , 10 <sup>th</sup> Nov	Progress Check
		11 <sup>th</sup> Nov	Second Meeting
		18 <sup>th</sup> Nov	Reviewing Session
		21 <sup>st</sup> Nov	Interview (Both parents)
Family 11 (Case 9)	11 <sup>th</sup> Nov – 5 <sup>th</sup> Dec	11 <sup>th</sup> Nov	First Meeting
		14 <sup>th</sup> , 18 <sup>th</sup> , 21 <sup>st</sup> , 25 <sup>th</sup> Nov	Progress Check
		25 <sup>th</sup> Nov	Second Meeting
		2 <sup>nd</sup> Dec	Reviewing Session
		5 <sup>th</sup> Dec	Interview (mother)
Family X		30 <sup>th</sup> Aug	First Meeting
		8 <sup>th</sup> Sep	Cancelled joining
Family Y		27 <sup>th</sup> Sep	First Meeting
		30 <sup>th</sup> Sep	Cancelled joining

## **Appendix-C Interviews with Parents: Topic Guide**

### **1. General information about the family**

- Family: size, structure (nuclear and extended), ages, gender)
- Socio-economic status (occupation, income/wealth, home location/ownership and occupations

### **2. Non-disabled children**

- Age, gender.
- Roles within the family
- Understanding of autism
- What are some of the things you have experienced with your children?

### **3. Understanding and experience of Autism (own and non-disabled child's)**

- Diagnosis of autism: age of diagnosis?, where diagnosed? medical classification, nature of condition/impairment (e.g. communication)
- How much does your non-disabled child know/understand about autism?

### **4. Relationships between autistic and non-disabled child(ren)**

- How does your non-disabled child get on with your autistic child?
- How does your non-disabled child interact with your autistic child?
- How does your non-disabled child communicate with his/her autistic sibling?
- Is your non-disabled child affected by their sibling's autism? If yes, how?
- Do your children experience problems in their sibling relationship (beyond what you might expect of any siblings)?
- (for non-disabled children in secondary school), how has their relationship changed over time?
- Do you think it would make any difference if your non-disabled child was younger/older than his/her autistic sibling?
- If your children were same gender do you think it would make any difference to their relationship?

### **5. Family life**

- How would you describe your relationship with:
  - [name of autistic child]
  - [name(s) of non-disabled child(ren)]
- Do you think your (non-disabled) child's life would be different if his/her sibling was not autistic?
- What role (if any) do members of your extended family play in the care of your children?
- When you are not with [autistic child] who takes care of him/her and where?
- What role (if any) do members of your extended family play in the care of your children?
- How do your neighbours respond to your child's autism?
- How do members of the public respond when [non-disabled child] goes out with [autistic child]
- How do members of the public respond when you go out as a family with [autistic child]

- How will [autistic child] be cared for as an adult? Who will take responsibility for him/her?

#### **6. Friends**

- Does [non-disabled child] have any close friends? How many?
- Do you know these friends?
- Do his/her friends know s/he has an autistic sibling? If not, why not?
- Do any of your non-disabled child's friends visit your home? If not, why not?
- Does your non-disabled child behave differently with his/her friends in the presence of his/her autistic sibling?

#### **7. School**

- Do your children go to the same school?
- Which schools do your children attend?
- What grades are your children in at school?
- (for young people aged 13 over) How did s/he manage the transition from primary to secondary school ?
- How is your non-disabled child getting on academically at school?
- Does your non-disabled child(ren) receive any special support services from the school?

#### **8. Support services**

- Does your family receive any benefits or allowance? From whom? For what? If yes, how much?
- Does anyone in your family receive any other related support services? If not, why not?
- Are you aware of any sibling support groups? If yes, please tell me.
- Does your non-disabled child attend a siblings support group?
- What sort of support or other help do you feel:
  - your autistic child needs?
  - your non-disabled child(ren) need?

Do you have any other comments about your non-disabled child's experiences or support needs?

**Appendix-D** Brief Summary of Video diary and Home movie Content and Context

<b>Video diaries</b>		<b>Home movies</b>	
Filming Location	Number of video diaries	Filming Location	Number of Home movies
Home	76	At Home	79
Out of Home	0	Supermarket	5
		Street	6
		Restaurant	3
		Barber shop	2
		Park	4
		Car	3
		Amusement park	5
		Children playing ground	3
<b>Total</b>	<b>76</b>	<b>76</b>	<b>110</b>

<b>Times of Recording</b>	<b>Number of Video diary</b>	<b>Number of Home movie</b>
7:00 - 12:00	0	13
12:00 - 18:00	0	24
18:00 - 24:00	73	71
24:00 - 7:00	3	2
<b>Total</b>	<b>76</b>	<b>110</b>

<b>Topics in Video Diaries</b>	<b>Percentage of Video Diary</b>
Autistic child	45.4%
Describing daily activities	23.2%
Non-disabled siblings themselves (e.g. personal feelings & opinions, school, studying, future, wishes)	19.4%
Parents	5.7%
Friends	3%
Special family events	2%
Extended family	1.3%

<b>Subjects in Home Movies</b>	<b>Percentage of Home movie</b>
Autistic children only	39.3%
Parent(s) and autistic child only	25.5%
Child and autistic sibling	9%
Parents only	3.6%

Non-disabled sibling only	4.5%
Extended family (no facial identifications)	2.7%
Non family member (e.g. friends, people in public areas) (no facial identifications)	5.4%
Others (e.g. TV, toys, books, clock etc)	10%

<b>Content of Home Movies</b>		<b>Percentage of Home movie</b>
Filmed at home	Autistic child's behaviours (8.3% show 'challenging behaviours'-e.g. tantrum, sleeping disturbance)	35.4%
	Interaction between parents and autistic child	15.4%
	Interaction between non-disabled child and their autistic sibling	9%
	Studying (non-disabled child)	4.5%
	Parent(s)' domestic work	2.5%
Filmed out of home	Outdoor activities of autistic sibling	8.1%
	Outing with family	6.3%
Filmed in/outside home	Activities with friends of non- disabled child	1.6%
	Family meal time (at home or in restaurant)	7.2%
Others (e.g. TV cartoon programme, rooms in house etc)		10%

## **Appendix-E** *Analysis, Coding and Transana* (version 2.10)

Once the fieldwork was concluded, I had in my possession a vast amount of visual data. In order to make the task of data analysis manageable, I undertook initial analysis with the aid of a computer programme designed specifically for visual data: *Transana* (version 2.10).

*Transana* is a web-based free qualitative computer-based analysis computer tool, which allows a researcher to work with large collections of audio and video data. It provides various tools for organizing, analyzing, and retrieving videos, segments of videos, and transcriptions of videos. *Transana* was originally created by Chris Fassnacht. It is now developed and maintained by David K. Woods at the Wisconsin Center for Education Research, University of Wisconsin-Madison (USA). It is designed to handle large video collections and to facilitate their management combining audio and video with transcripts.

1. For working with digitalised video file in *Transana*, the video file was loaded into *Transana*'s main interface. To do this, it first created a 'Series' (from Case 1 to Case 9), which holds a group of related video files. Then it created an 'Episode', which is where I specified sections of children's video diaries and home movies (media file) to analyze. In this process, *Transana* is marketed as working with MPEG-1, MPEG-2, and most AVI video formats, as well as MP3 and WAV audio formats (see 3 iii below).
2. I transcribed the spoken words from the video diaries/home movies and changed into English phonetic characters. The transcripts were used as a written record that corresponds to the video diaries and home movies being analyzed. Then, I used 'Time codes', to link corresponding video and audio files and transcripts in *Transana*.
3. I could identify a particular segment of video as being analytically interesting. The 'Clips' are the primary analytic units (selected video footage) in *Transana*. Clips that are analytically similar are gathered together into 'Collections'. The selected Clips could show phenomena of daily life (e.g. meal time, sleeping, interaction style). I created and applied a 'Keywords' to selected video clips. As this stage, my coding was very general. I had coded lengthy video footage with Keywords (referring to key

concepts, e.g. 'family life') and sub-Keywords (referring to various branches e.g. shared care, parental attention). I could use a synchronized 'search' function (between media, audio file and transcripts) to look for video footage assigned with particular Keywords, once I had coded a substantial body of work. It was very time consuming work but I was able to embark upon more detailed coding of video clips. I was thus able to merge or change each Keyword and sub-Keyword.

*Transana* does not work automatically. A researcher must sit, watch the video and make notes in *Transana*. I found several limitations in using *Transana*:

- i) a lack of Unicode characters support made it impossible to use non-standard-Latin characters in transcription,
- ii) I encountered bugs (e.g. clicking on 'Select clip text' produced an 'Unhandled Exception' or crashed),
- iii) management of multimedia data presented unexpected challenges in data acquisition, management, analysis, transparency and dissemination. For example, *Transana* could support only limited types of visual data (e.g. MPEG type one or two).
- iv) In terms of data transparency, I saved all data processes to track the processes involved in the whole research journey (e.g. viewing coding development and structures). All research processes (transcripts, Collection, keywords linking to particular video segments) were stored internally in a MySQL database, and there should have been no problem in saving the data. However, *Transana* did not offer a usable exchange format for its data and importing data was problematic.
- v) I found technical problems related to the Keyword and video footage selection system. But I had already conducted a considerable amount of analysis using *Transana* (ver. 2.10). For instance, coded video footage linking to Keyword could not be sorted directly within *Transana*.

## Appendix-F Guide to Romanization

The Anthology used the new Romanization system proclaimed by the Ministry of Culture and Tourism for terms in Korean:

1) Vowels are transcribed as follows:

Korean Letter (monophthong)	Shown by	Korean Letter (diphthong)	Shown by
ㅏ	a	ㅑ	ya
ㅓ	eo	ㅕ	yeo
ㅗ	o	ㅛ	yo
ㅜ	u	ㅠ	yu
ㅡ	eu	ㅝ	yae
ㅣ	i	ㅞ	Ye
ㅘ	ae	ㅜㅓ	wa
ㅙ	e	ㅜㅕ	wae
ㅚ	oe	ㅜㅗ	wo
ㅜㅜ	wi	ㅜㅛ	we
		ㅟ	Ui

**Note 1:** ㅟ is transcribed as *ui*, even when pronounced as *i*.

**Note 2:** Long vowels are not reflected in Romanization.

2) Consonants are transcribed as follows:

- Plosives(stops)

Korean Letter	Shown by
ㄱ	g /k
ㄲ	kk
ㅋ	K
ㄷ	d / t
ㄸ	Tt
ㅌ	T
ㅍ	b / p
ㅑ	pp
ㅑ	p



- Affricates

Korean Letter	Shown by
ㅈ	j
ㅉ	jj
ㅊ	ch

- Fricatives

Korean Letter	Shown by
ㅅ	s
ㅆ	ss
ㅎ	h

- Nasals

Korean Letter	Shown by
ㄴ	n
ㅁ	m
ㅇ	ng

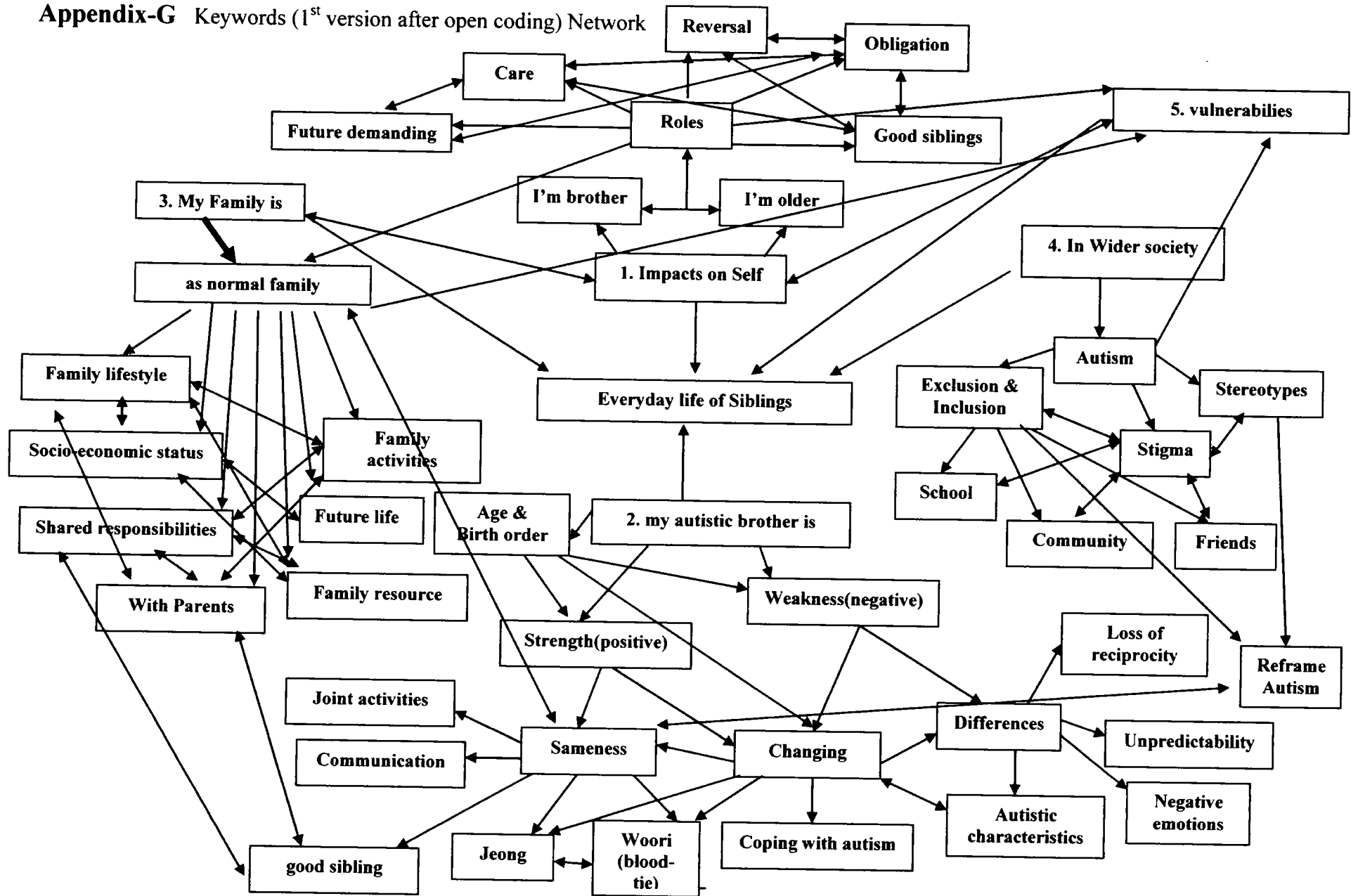
- Liquids

Korean Letter	Shown by
ㄹ	r / l

**Note 1** : The sounds ㄱ, ㅋ, and ㆁ are transcribed respectively as *g*, *d*, and *b* when they appear before a vowel; they are transcribed as *k*, *t*, and *p* when followed by another consonant or form the final sound of a word.

**Note 2** : ㄹ is transcribed as *r* when followed by a vowel, and as *l* when followed by a consonant or when appearing at the end of a word. ㄹㄹ is transcribed as *ll*.

**Appendix-G** Keywords (1<sup>st</sup> version after open coding) Network



The above figure is an example (Case 9) of a Keyword network derived from *Transana*. The central Keyword is 'everyday life of siblings', from which the other keywords stem: 1) one keywords refers to 'impact on self', 2) the other to the 'my autistic brother is' described by the siblings, 3) 'My family is', 4) 'in wider society', and v) 'vulnerabilities'. It goes on to present 'everyday life of siblings'.

Here, there is an obvious interrelation, and intrarelation between Keywords and sub-keywords. For example, 'obligation' can be interrelated with the other four sub-keywords (future demands, care, good siblings, reversal). 'Role' can also be intrarelated with 'lose and gain' under 'family'. Moreover, there is an obvious over-lap as some of 'good siblings' could appear as sub-keywords stemming from 'sameness'.

In *Transana*, I was able to call up the data I had on a video footage by Keywords but I could not call up specific video footage by selecting a Keyword because of coding problems with the programme. Instead, I used 'search' function on transcripts to call up specific video footage.

It was not possible to print out keywords in this way because *Transana* does not support visual presentation of the Keyword system. In particular, *Transana* does not support a hierarchical coding system (called 'tree node' in *Nvivo*) and could not elicit any relationships between Keywords and sub-Keywords. Moreover, it was not possible to print all keywords in this figure because of the number of sub-keywords within the figure. For example, I could not present all the sub-keywords stemming from 'vulnerabilities' in this figure. To reproduce this in its entirety would make it profoundly difficult to interpret.

In short, I compared keyword networks to identify similarities and differences between the 9 Cases.

## Appendix-H

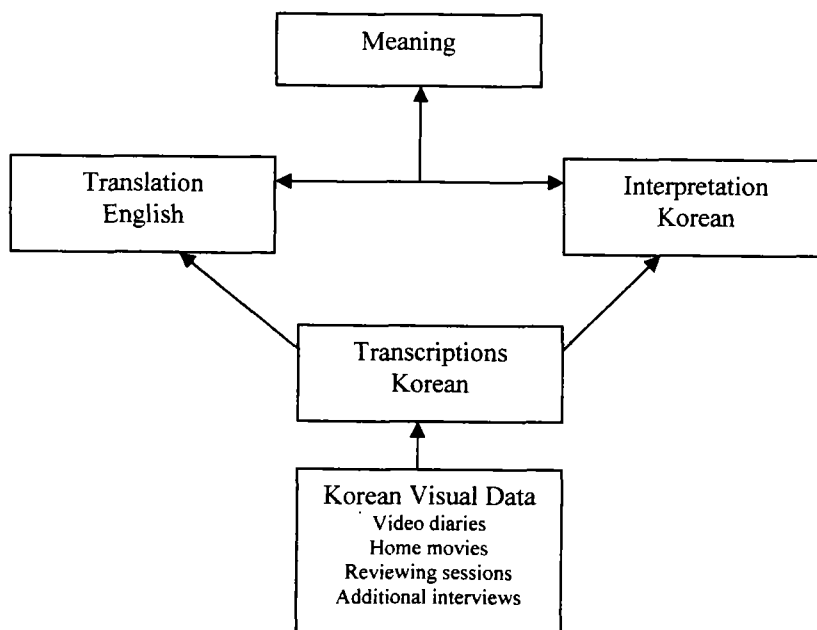
### The Process of Back-Translation from Korean to English (see below Figure)

The Korean texts were translated into English by a bilingual translator

Another translator translated the English version back into Korean. There was no consultation between the translators.

The researcher examined the Korean version and back-translated English version to identify any discrepancies in meaning

For Korean words that could simply not be translated into English, the researcher and academic supervisor discussed the concepts involved to achieve an interpretation in the English language capturing the closest possible meaning. In this process, the researcher often returned to the video data to check and to verify the participant's words and images.



## **Appendix-I Ethical Approval**

Durham University Ethics Advisory Committee formally delegates to the Ethics Sub-Committees of Departments/Schools/Faculties the authority to assess and determine applications (with a copy of the consent form and information sheet to be given to participants) for all teaching, learning, research and other projects which involve human participants and/or raise ethical issues where these applications are from the Department/Schools/Faculties staff or students

([www.dur.ac.uk/committees/ethics/annex/](http://www.dur.ac.uk/committees/ethics/annex/)).

The completion of application forms for ethical approval followed the guidelines set out in the Postgraduate Research Handbook. These include adherence to a recognized ethical code, and the British Sociological Association Code of Ethics was used to inform the application.

Key elements are that:

- The physical, social and psychological well-being of research participants should not be adversely affected by the research;
- Research relationships are to be characterised, whenever possible, by trust and integrity;
- As far as possible, participation in research should be based on the freely given informed consent of those studied. This implies a responsibility to explain in appropriate detail, and in terms meaningful to participants, what the research is about, why it is being undertaken, and how it is to be disseminated and used;
- Research participants should be made aware of their right to refuse participation whenever and for whatever reason they wish;
- Research participants should understand how far they will be afforded anonymity and confidentiality and should be able to reject the use of data gathering devices such as tape recorders and video cameras;
- The anonymity and privacy of those who participate in the research process should be respected. Personal information concerning research participants should be kept

confidential. In some cases it may be necessary to decide whether it is proper or appropriate even to record certain kinds of sensitive information;

- Where possible, threats to confidentiality and anonymity of research data should be anticipated by researchers. The identities and research records of those participating in research should be kept confidential whether or not an explicit pledge of confidentiality has been given;
- Researchers should clarify whether, and if so, the extent to which research participants are allowed to see transcripts of interviews and field notes and to alter the content, withdraw statements, to provide additional information or to add gloss on interpretations;
- Where access to research settings is via a gatekeeper, researchers should adhere to the principle of obtaining informed consent directly from the research participants to whom access is required, while taking into account the gatekeeper's interests;
- It is incumbent upon researchers to be aware of the possible consequences of their work. Wherever possible they should attempt to anticipate, and to guard against, consequences for research participants that can be predicted to be harmful. Researchers are not absolved from this responsibility by the consent given by research participants;
- There are serious ethical and legal issues in the use of covert research methods and supervisors' agreement must be gained that such an approach is appropriate.

With the exception of the latter point that was not relevant to this research study, all these considerations were addressed in the application for ethical approval and the Head of SASS, as Chair of the SASS Ethics sub Committee raised no concerns. A copy of the ethical approval for this doctoral research was submitted to Graduate School alongside the doctoral thesis.

**University of Durham  
School of Applied Social Sciences**

**RESEARCH ETHICS AND RISK ASSESSMENT FORM A**

All research projects must be assessed for ethical issues and risks to the researcher(s)<sup>1</sup>. Form A starts this process and must be submitted by the principal investigator<sup>2</sup> for all projects that staff or students of the School intend to undertake. The form must be approved before any data collection begins. It is your responsibility to follow an appropriate code of ethical practice, such as those of the British Sociological Association or Social Research Association<sup>3</sup>, and to acquaint yourself with safety issues by consulting an appropriate reference such as *Social Research Update: Safety in Social Research*<sup>4</sup>. Data should be handled in a manner compliant with the Data Protection Act. Researchers undertaking studies in an NHS or social services setting must abide by the *Research Governance Framework for Health and Social Care*<sup>5</sup>.

**Section I Project outline**

*Name of investigator:* SE KWANG, HWANG

*Dissertation/project title:* Seeing to Know: everyday life of siblings of brother or sister with autism

*Degree and year (students only):* PhD / 2<sup>nd</sup>

*Estimated start date:* September 2005

*Estimated end date:* January 2006

*Summary (up to 250 words describing main research questions, methods and brief details of any participants)*

Evidence about effects on a child's psychological and social development of having a disabled sibling is equivocal. Severely disabling conditions with accompanying behavioural difficulties such as autism may have a particularly profound impact. Previous research has employed quantitative methods: surveys, standardised measures and semi-structured interviews with parents. Very few have elicited the siblings' own views and experiences; none of these concerned autism.

This study adopts an ethnographic methodology. It aims to be child-led, engaging the siblings as informants about their own lives, using the innovative method of video diaries supplemented by an interpretive interview and action techniques.

Through these methods, this study aims to develop a deeper understanding of sibling issues in families of children with autism and to identify the needs of siblings. It will evaluate the extent to which family support services can meet these needs, and compare family policies in England and Confucian culture (South Korea)

<sup>1</sup> See University of Durham School of Applied Social Sciences *Research Ethics and Risk Assessment Policy and Procedures*, March 2005

<sup>2</sup> In the case of student research, the principal investigator is always the student.

<sup>3</sup> [http://www.britisoc.co.uk/new\\_site/index.php?area=equality&id=63](http://www.britisoc.co.uk/new_site/index.php?area=equality&id=63); <http://www.the-sra.org.uk/Ethicals.htm>;

<sup>4</sup> <http://www.soc.surrey.ac.uk/sru/SRU29.html>

<sup>5</sup> <http://www.dh.gov.uk/assetRoot/04/01/47/57/04014757.pdf>

**Section 2 Ethics checklist** (please answer each question by ticking as appropriate)

	Yes	No
1. Does the study involve participants who are vulnerable or unable to give informed consent (e.g. children under 16, people with learning disabilities)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
2. Will it be necessary for participants to take part in the study without their knowledge/consent (e.g. covert observation of people in <i>non-public</i> places)?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
3. Could the study cause harm, discomfort, stress, anxiety or any other negative consequence beyond the risks encountered in normal life?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
4. Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
5. Will the project involve the participation of patients, users or staff through the NHS or a social services department?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
6. Are appropriate steps being taken to protect anonymity and confidentiality? (in accordance with an appropriate Statement of Ethical Practice).	<input checked="" type="checkbox"/>	<input type="checkbox"/>

If you have answered 'yes' to any of questions 1-5, you must complete Form B and attach Form A as a cover sheet. Both Form A and Form B must be submitted for approval (see Section 5). Now go to Section 3.

**Section 3 Risk assessment checklist**

	Yes	No
1. Does the study involve practical work such as interviewing that requires the researcher(s) to travel to and from locations outside the University?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
2. Does the study involve accessing non-public sites that require permission to enter?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
3. Are there any identifiable hazards involved in carrying out the study, such as lone working in isolated settings?	<input type="checkbox"/>	<input checked="" type="checkbox"/>

If you have answered 'yes' to any of questions 1-3, you must consult the University's Health and Safety Manual Section F1 at: <http://www.dur.ac.uk/healthandsafety/F1-Fieldwork3.htm#App2>  
You must complete two forms available in appendices 2 and 3 at this web site: *Fieldwork – risk assessment* and *Fieldwork health declaration*. These forms must be submitted with Form A.

**Section 4 Signature**

For taught and research students Form A must be approved and signed off by your supervisor. For staff, the principal investigator must sign the form.

Signature: *Helen Charnley*

Date: *27 July 2005*

**Section 5 Next steps**

1. If *only* Form A is required, students must submit the completed form with their project/dissertation and staff must file the completed form in the School Office ethics file. Nothing further is required.
2. If the Fieldwork forms are required, attach and submit these with Form A for approval.
3. If Form B is required, attach Form A as a cover sheet and follow the instructions on Form B.

Forms must be submitted for review and approval as follows:

- |  |   |
|--|---|
| • Students on Social Work programmes   | Secretary of the Social Work Ethics Committee |
| • All other students on taught courses | Your supervisor                               |
| • Research students                    | Director of Graduate Studies                  |
| • Staff                                | Chair of Research Committee                   |



**School of Applied Social Sciences  
University Of Durham**

**RESEARCH ETHICS AND RISK ASSESSMENT FORM B**

*Form A* must be attached to this form as a cover sheet. *Form B* must be completed if you have answered 'Yes' to any of questions 1 to 5 in Section 2 of Form A. If your project requires approval from an NHS or Social Services ethics committee, you must first obtain this approval. Once approval has been granted, including meeting any conditions, you must submit the approved form together with evidence of this approval with Form B. If you are submitting an NHS or Social Services ethics form, you only need to complete Sections 1, 2 and 5 of Form B. This form must be approved before data collection begins.

**Section 1**

1. Name of Principal Investigator: SE KWANG, HWANG
2. Does the research require ethical approval from the NHS or a Social Services Authority?  
Yes  No
3. Might the proposed research meet the definition of a clinical trial? It may do so if it involves studying the effects on participants of drugs, devices, diets, behavioural strategies such as exercise or counseling, or other 'clinical' procedures.  
Yes  No

**If 'Yes', a copy of this form must be sent to the Insurance Officer, Treasurer's Department. Tel: 0191 334 6968. Insurance approval will be necessary before the project can start and evidence of approval must be attached with this form.**

**Section 2 Checklist of attachments**

*For all applicants tick the documents you are attaching with this form:*

- Form A .....
- An approved NHS or Social Services Ethics Form (if applicable) .....
- Evidence that your NHS or Social Services Ethics Form has been approved (if applicable) .....
- Information sheet for participants (if individual consent is to be obtained) .....
- Consent form (if individual consent is to be obtained) .....
- Fieldwork Risk Assessment (if applicable) .....
- Fieldwork Health Declaration (if applicable) .....
- Confirmation of insurance cover (if applicable; see question 11) .....

*For students only:*

- Letter of invitation to participants .....
- Letter of invitation to leaders/managers .....
- Leaflet/Flyer for all relevant parties attached .....
- Consent form .....
- Questionnaire .....
- Interview guide .....
- Written confirmation from all agencies involved in the study that they agree to participate .....

**Section 3 Project details**

1. How many research participants will be involved in the study? 11 families
2. How will they be selected? (e.g. age, sex, other selection criteria or sampling procedure)

Families will be recruited from church-based voluntary social service agencies in South Korea. Each family will be included the parent, one or more siblings and child with autism. In particular, sibling's age is between 5 and 15. The grandparent or extended family members will also be able to participate.

3. Are there any people who will be excluded? If so state the criteria to be used  
No

4. Who are the participants? (e.g. social services clients, NHS patients, users of a specific service)  
church-based voluntary social service clients

5. Who will explain the investigation to the participant(s)?

I will post information package to interested participants. This will explain that they are voluntary participants in a study and that their privacy and confidentiality will be maintained and how I plan to carry out research, why I am doing this project, and how the information I gather will be used. What is more, If I does not know in advance the questions that a participant might be asked, or what potential risks might be involved in the future, this will be made clear to the participant at the information sheets. I will then visit the parents at home and answer any further questions

6. How and where will consent be recorded?

A consent form will be included in information package. During the home visit, I will ask the participants to sign a consent form which states the person volunteers to participate in a research. In particular, I have been paid attention how best to obtain consent with children. It might be appropriate to seek assent from children (Alderson & Goodey, 1996; Connors & Stalker, 2003). I will, therefore, make information package and consent form for children, which asks their children's assent to taking part in this work. Verbal assent will be sought before and after the interviews with the children. Consent takes place not only before a first meeting, but during whole research stages.

7. What steps will be taken to safeguard the confidentiality of records and to ensure compliance with the requirements of the Data Protection Act.?

The uses to which the audio and video recordings will be put compact disk under which security access to, and use of, them may be controlled by researcher only. Written data and interview material will also be kept in locked filing cabinet in researcher's office. Families will be a given code number, and names will be kept separately.

8. Will non-anonymised questionnaires, tapes or video recordings be destroyed at the end of the project?

Yes  Go to qu. 11      No  Go to qu. 9      Not Applicable  Go to qu. 11

9. What further use do you intend to make of the material?

Research data will be used only for other relevant research and educational purposes in the future

10. Will consent be requested for this future use? Yes  No  Not Applicable

**Section 4: Risk or discomfort to participants**

11. What discomfort, danger or interference with normal activities could be experienced by participants? State probability, seriousness, and precautions to minimise each risk.

Risk/Discomfort	Probability	Seriousness	Precautions
Psychological harm	Research may induce mental and emotional stress. Qualitative interviews on sensitive topics with families may provoke powerful emotional responses.	Participants may create challenges, refusals, inversions and ironic behaviours.	Researcher should recognize participant's vulnerability, the danger still remained in the field. Researcher also tries to avoid overpowering, over-implementing or over-interpretation.
Invasion of Privacy	Family video may contain very private information.	Research may increase vulnerability	Researcher must inform that they are not obliged to take part, and it includes their right to withhold information on video recording.

**Section 5 Signatures**

Principal Investigator: *[Signature]* Date: 27 July 2005  
 Supervisor/tutor (students only): *[Signature]* Date: 27 July 2005

**Next steps**

This form with all attachments and Form A at the front should be submitted for approval as follows:

- Students on Social Work programmes: Secretary of the Social Work Programme Ethics Committee
- All other students on taught courses: Your supervisor
- Research students: Director of Graduate Studies
- All Staff: Chair of Research Committee

**FOR OFFICE USE ONLY**

**SECTION 6: OUTCOME OF APPLICATION**

a) The proposal is satisfactory and should be accepted as it stands.	<input checked="" type="radio"/> YES / NO
b) The proposal should be accepted subject to the conditions noted below.	YES / NO
c) The applicant should submit a new proposal in the light of the comments noted below.	YES / NO

**Comments** (for forwarding to the applicant)

Signed     T Blackman     Date     10/8/05      
 Name (block capitals)     PROF TIM BLACKMAN    

A COPY OF THE APPROVED FORM MUST BE KEPT ON FILE.  
 STUDENTS MUST SUBMIT A COPY OF THE APPROVED FORM WITH THEIR  
 PROJECT/DISSERTATION.