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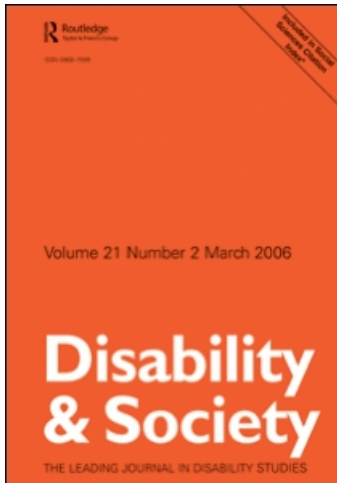
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Making the familiar strange and making the strange familiar: understanding Korean children's experiences of living with an autistic sibling

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Based on the findings of a small-scale study using visual ethnographic techniques with nine South Korean children, this article explores the role of culture in understanding autism. While autism is embedded within the 'strange' and 'unfamiliar', linked to exclusion and discrimination in Korean society, the children focussed on reframing their experiences of living with autism as 'ordinary'. Despite the limitations of the small sample, the richness and depth of data generated by children themselves offers new insights into children's interpretations and experiences of autism and raises interesting questions for cross cultural research in the field of disability.

Keywords: autism; Korea; Confucian familism; culture; children; siblings

Introduction

'I'm sorry, he's autistic, please don't mind his behaviour' – the whispered words of a white English father attempting to explain his son's noisy behaviour in a supermarket to the lead author of this article. The staring of many shoppers and the father's attempts at explanation poignantly highlighted public perceptions of autism as 'strange'.

Although autism is widely recognized in the literature as a broad range of pervasive developmental disorders, its true prevalence is not known and its precise causes still not understood (see Rutter 2005; Lewis 2003). The Korean word for autism, *Chapae*, means 'being closed in on oneself' (Grinker 2007, 237). In Korea, autism has been officially categorized as a disability since 2000. The Korean movie *Mal-a-ton* [marathon], about a young autistic marathon runner, has had a profound effect on autism awareness since 2005. However, the prevalence of autism in Korea is unknown and many autistic children remain hidden from the community by their families.

This article begins by discussing a theoretical framework for understanding the social implications of autism in Korea, drawn from the cultural model of disability (Devlieger, Rusch, and Pfeiffer 2003). It goes on to describe a visual ethnography of nine Korean children living with autistic siblings, exploring the ways in which autism was experienced and conceptualised by non-disabled siblings.

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Culture and disability: the literature

Disability has been viewed from a variety of perspectives. Medical perspectives see disability as an individual problem tied to the functional limitations of bodies (Swain, French, and Cameron 2003) with an emphasis on deficit and impairment rather than the needs of the person (Crow 1996). As Linton (1998, 11) has argued, this creates insurmountable barriers of negative stereotypes, treating human variance as deviation from the norm, deficit, pathological condition, individual burden, and personal tragedy.

In challenging this perspective the disability rights movement has reconceptualised disability as social oppression, drawing a distinction between disability and impairment (Oliver 1996). The central tenet of this movement is that disabled people experience social exclusion as a result of physical, environmental, legal, cultural and attitudinal barriers (Swain, French, and Cameron 2003). Disability is perceived not as personal tragedy but as a positive personal and collective identity (Swain and French 2000). Despite the advances of the disability rights movement, critics argue that this perspective fails to address the lived experience of impairment and the development of individual identities that go beyond 'disabled' (Shakespeare and Watson 2001). Ahmed (2000) has argued that the social model of disability may seem over-westernized to many for whom interdependence, mutual support and reciprocity are the hallmarks of social and family relationships.

The most recent development in theorizing disability is the emergence of a cultural model in which disability is defined as a cultural construct (Priestley 2001; O'Hara 2003; Daley 2002; Welterlin and LaRue 2007). While the social model views disability as the product of social oppression, the cultural model understands disability as being inherent within socio cultural systems (Cason 2007). Bates and Plog (1991) argue that cultural expectations reflect systems of shared beliefs, values, customs, behaviours, and artefacts used by members of a society to cope with their world and with one another. In contrast Geertz (1993) sees culture as the context of everyday lives so that descriptions of culture must be cast in terms of constructions and interpretations to which people subject their experiences (Peters 2000, 587).

For the purpose of this article, 'culture' is understood both as the construction and reconstruction of meaning. Our emphasis on cultural expectations serves to highlight differences in the construction and interpretation of disability that exist between and within different cultures. In this sense, disability can represent experiences that are both the 'same and different' (Devlieger, Rusch, and Pfeiffer 2003, 10). Gilson and Depoy (2000) argue that disability identity can be internally derived or externally imposed depending on how disability is viewed within specific cultures. Conceptualising disability as environmental and bodily variations (Snyder and Mitchell 2006), we see how disability is interpreted differently across cultures determined by a number of variables concurrently, rather than by single variables such as the presence of impairment (Groce 2000). In Euro-American modern thinking, disability has been described as the assumption of the desirability of equality (Whyte and Ingstad 1995) with heavy emphasis on achieving the independence of people with disabling conditions (Fine and Asch 2000). Groce (2000) has argued that western studies seeking to determine the social status of all disabled people, easily miss differences in social expectations, for instance, between those who are blind and those who are mobility impaired. In many non-western cultures, impairment is commonly perceived as a manifestation of misfortune caused by others, oneself or God, as fate, or the unhappy

consequence of misdeeds in a previous existence (Yoshida, Li, and Odette 1999; Miles 2000; Choi and Lam 2001).

Culturally-embedded stereotypes of disability affect the ways in which disabled people are seen and see themselves, in turn affecting the ways in which family members, friends, and others interact with disabled people (Peters 2000; Rao 2006). 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). Barnes and Mercer (2003) argue that negative attitudes and behaviour towards disabled people may be extended to other family members as a 'courtesy stigma'. Similarly, Burke (2004) refers to the experiences of siblings of disabled children as 'disability by association' arguing that 'the experience of childhood disability becomes the property of the family as each member shares the experiences of the other to some degree' (23).

Cultural interpretation of disability in Korea

Processes of modernization and globalization have brought western cultural influences to Korea (Yim 2002), and disability welfare policies have been introduced and developed (Kim and Ross 2008) based on notions of universal human, and disability, rights. Despite recognition of the needs and entitlements of disabled people and their families (e.g., the Welfare Act for Persons with Disabilities), disability remains a strong signifier of dishonour and shame linked to stigma, discrimination and exclusion (Choi and Lam 2001; Won, Krajicek, and Lee 2004; Kim and Min 2006). Deep-rooted beliefs about disability, manifested through fatalism or shamanistic thinking (Kwon 2000) remain a source of shame to the family and their ancestors (Kim and Kang 2003). There is also evidence of persistent belief in disability as the result of inauspicious sites for graves and houses, punishment for sins committed in a previous existence, the responsibility of ancestors or wicked ghosts (Erickson, Devlieger, and Sung 1999). Disability is still associated with 'fatal uselessness', seen as contemptuous and a life-long tragedy (Seo 2005). Disabled people are treated as second-class citizens rather than people with rights to be included in mainstream society (Kim and Davis 2006). A report by the Korean Institute for Health and Social Affairs (KIHASA 2005) suggested that 86.7% of disabled Koreans believed they were subject to either discrimination or human rights abuses. Grinker (2007) found that the principle of *Ijil* (difference), with its negative connotations of 'unnatural' or 'unwanted' lies behind popular attitudes to disability in Korea and 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 for difference' (239). *Ijil* is closely related to the notion of shame that is also associated with *Chemyon* (saving face). Choi and Lee (2002) and Lim (2002) 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 2000) not only to the self but to other members of the family and community (Lee 1999; Brown and Brown 2006). In the family context, saving or losing *Chemyon* is linked to the success or shame of the whole family, not only individual members. Success in individual life brings the highest honour for one's family. But individual failure

represents the worst form of dishonour for the family. In this context, disability, illness or impairment can bring shame and humiliation rendering the family ‘improper’ or ‘incomplete’ in Korea (Seo 2005, 68–9).

More positive terms for disability (*Jang-ae*), and disabled people (*Jang-ae-in*) have been officially adopted since 1990, but the use of offensive terms persists reflecting and reinforcing negative attitudes to disability (Choi and Lam 2001; Choi and Lee 2005). Because of prevailing negative attitudes and pejorative terminology, many disabled people, and their families, avoid disability related identities (Kwon 2005) and many parents of disabled children avoid registering their children as disabled (Kim and Kang 2003). In the following section we present the findings of an empirical study revealing a dissonance between the introduction of social policy based on western values and the daily reality of life for Korean families with disabled children.

The study

Conducted in two cities in Korea, this study is the first to use visual ethnographic methods to explore children’s experiences and perspectives of living with an autistic sibling (see Figure 1).

Nine children, aged 7- to 15-years-old, and their parents were recruited using a snowball sampling strategy starting with three parent support groups where information packages and consent forms were given to families (Table 1).

Five boys and four girls used a personal multimedia player/recorder (PMP) to make video diaries and home movies of their everyday lives. Each family took part in a briefing session to discuss the study, data collection methods, ethical issues and implications of participation. This session provided the opportunity to check parents’ and children’s understandings, to discuss concerns and to reconfirm informed consent. The children and their parents were trained in the use of the PMP to maximize the

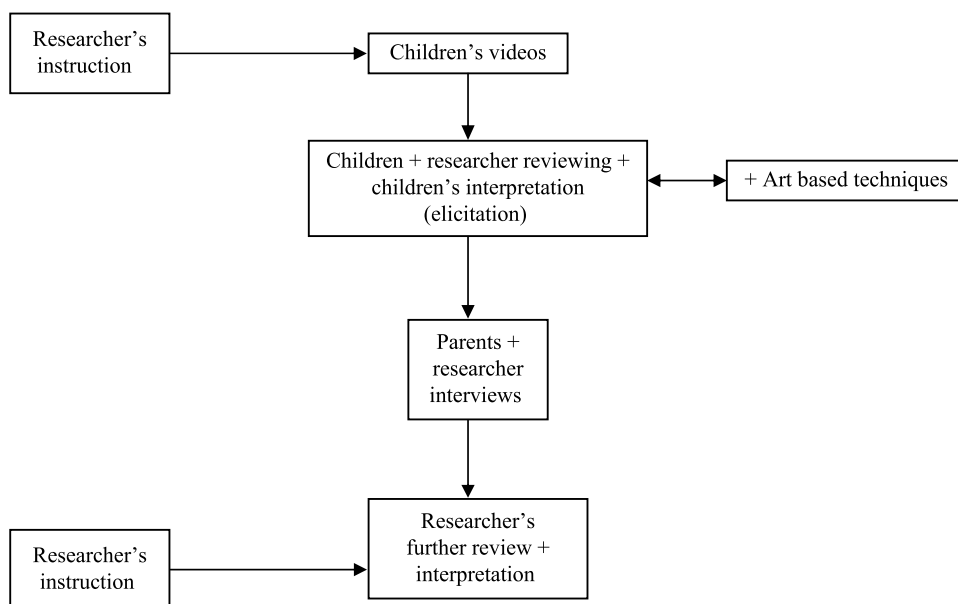


Figure 1. Collecting data and generating children’s knowledges (see MacDougall 2006).

Table 1. Study participants.

Child	Age	Gender	Autistic sibling	Age	Gender	Number in family	Type of residence	Parents' occupations
A1	15	F	A2	17	M	4	Apartment	(1) Shop owner (2) Part-time classroom assistant
B1	7	F	B2	9	M	4	Apartment	Technician
C1	13	M	C2	18	M	4	Apartment	(1) Teacher (2) Part time teacher
D1	8	F	D2	6	M	5	Apartment	Professional
E1	12	M	E2	10	M	4	Apartment	Banker
F1	8	F	F2	9	F	4	House	Small business (transport) owner
G1	12	M	G2	8	M	4	Apartment	Shop owner
H1	13	F	H2	11	M	4	Apartment	(1) Practice vicar (2) Part time classroom assistant
J1	13	M	J2	10	M	4	Apartment	Civil servant

'useful' visual data collected while maintaining the free-form approach to filming. The children had control over what was recorded, edited and deleted before viewing and discussing with the researcher. This approach represents a move away from the typical relationship between viewer (audience), researcher and participant (see MacDougall 1978). The children as both researchers and viewers (interpreters) were the primary producers of knowledge about their own views and experiences (Alderson 2001, 151). The value of this approach lies in avoiding researchers' assumptions about children's capabilities, facilitating research 'with children' rather than 'about children' and illuminating different experiences of childhood (Young and Barrett 2001, 144). Parents were interviewed separately to provide their perspectives although this aspect of the study is not the focus of this article.

Ethical considerations

Serious ethical challenges are confronted when conducting visual ethnography with children. Informed consent from children and their parents was gained and regained throughout the research from initial consent to the children's participation in video elicitation sessions with the researcher. In the Korean cultural context characterised by strict family hierarchy, and only embryonic recognition of children's rights, it was notable that parents gave consent for their children to express their private thoughts and feelings to an outsider. Consent of the autistic children presented the biggest challenge. Although the literature indicates practical strategies for gaining the consent of children who are differently disabled in Euro-American contexts (see Walmsley and Johnson 2003), informed consent was obtained via parents in this study while principles of 'assent' (Hurley and Underwood 2003) were highlighted so that in making home movies, children and parents were asked to ensure that filming did not cause distress to the autistic siblings. This strategy was also informed by questions of cultural sensitivity and the central role of parents in being the guardians of children's decision-making in Korean society. Other ethical considerations concerned individual

privacy and confidentiality of data. 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 collection of video data that would be controlled by, and confidential to, the children. They were assured by arrangements for secure data storage, strict limitations on access and further consent requirements for the use of any (anonymised) images.

Where children filmed sensitive, private topics that caused embarrassment during elicitation sessions, great care was taken to ensure that the children 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 else. In essence, the children were given the opportunity to share evidence of scenes of daily life that they found challenging and wished to share with the researcher. But this was accompanied by the opportunity to erase those images.

Working with children as researchers

Video diaries were recorded in private allowing the children to express themselves freely and offering unique insights into unexplored worlds. The children spoke directly to the camera to convey their experiences, observations, thoughts and feelings of various daily episodes. In addition they made home movies depicting contextual information that is absent from video diaries, and capturing 'taken-for-granted everyday life' (Bloustien and Baker 2003). The children created 76 video diary entries totalling 80 minutes and 110 home movies totalling 13 hours 17 minutes.

To elicit deep information, analysis involved the children interpreting their own data. Using *video elicitation* techniques (Banks 2007), the children were invited to talk about their video diaries and home movies. Additional techniques (e.g., drawings, and spider-webs) were used to gain access to children's insights and to make the process fun. Care was taken to ensure that the children had access to private space during these activities with the researcher in order that they could feel confident that their parents would not see the material they had recorded. In order to ensure that children and their parents felt secure, parents were always present in another part of the house and the researcher never worked behind closed doors with the children.

Children's experiences of, and reactions to, autism

All nine children in the study were frequently confronted by negative public attitudes towards their autistic siblings and themselves. H1, a 15-year-old girl, described an episode with her autistic brother:

I saw my brother with middle school students and their boy friends. They imitated my brother's speaking. The boys imitated my brother's behaviours. I was really embarrassed but I had to bring him home safely. So I sat on a bench and phoned Mum 'I am in the park, but I cannot get him out [from the group]'. Later, I could not bear it any more, so I brought him home.

E1, a 12-year-old boy, had similar experiences with his autistic brother E2:

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.
 Interviewer: Never?
 E1: Almost never
 Interviewer: Why?
 E1: Because it could be dangerous.
 Interviewer: Dangerous? What do you mean?
 E1: People strangely keep on eye on us if my brother is around. I'm so embarrassed. So my parents are always with us.

Talking about the language surrounding autism in contemporary Korean youth culture, H1 discussed the use of the word *aeja*:

It is not an expression used about autism only. *Aeja* means more generally 'like disabled people', 'people with mental problems'. Like about people with mental problems, we use *aeja*... *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.

Five parents described how their non-disabled children were distressed by the dehumanizing terminology used about their autistic siblings. This pejorative use of language has been described by Gilson and Depoy (2000) as a power tool to demonstrate how disabled people are marginalised and devalued by the public. This study indicates that the children consistently struggled with the labelling of their autistic siblings as 'unusual' or 'abnormal'. These stereotypical, negative, perceptions outweighed the positive awareness acquired through the experience of living with a disabled sibling. For instance, A1 experienced judgemental reactions from her school friend: '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'.

None of the children talked openly about their siblings' autism, fearing that they may be subjected to pity. Two adolescent girls explained:

I do not want to talk about him. [If they] know, they pity me. 'Sympathy'... 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'. (A1)

I would be 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. (H1)

These findings suggest elements of shame and loneliness associated with an inability to escape the culturally constructed belief system about disability (Kwon 2000).

Nevertheless, the children's lives were not entirely bounded by autism. All nine children in this study argued that living with an autistic brother or sister is not the entirely negative experience implied by predominant cultural interpretations, 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.

Having an autistic sibling did not constitute a tragedy and the children's accounts did not focus solely on restrictions and hardships. Despite stereotyping, stigmatizing reactions, the children participated in various social activities with and without their autistic siblings. These were commonly described or shown in children's videos and included sports, shopping, dining out, family outings, playing (visiting) with friends, and after school clubs. D1 said:

- D1: I went to a music concert. Piano and other musical instruments.
 Interviewer: Did you go with D2?
 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.

Negative public attitudes to autistic children had not led to severe obstructions in these children's lives. Despite experiencing the stigma associated with their disabled siblings they pursued age-appropriate daily activities and their parents made conscious efforts to minimise restrictions in their daily lives.

Reframing experiences of life with an autistic sibling

Autism has been described as an enigmatic disorder (see Williams et al. 2008) visible only through behaviours and forms of communication that are widely interpreted as being problematic. 'Visibility' plays an important role in constructing understandings of disability (Titchkosky 2003). The lack of immediate visibility of autism results in strangers' expectations being constructed around notions of socially acceptable behaviour. All nine children in this study consistently experienced the explicit gaze of strangers towards their autistic siblings and the family in public settings. A1 described being 'stared at' when she was out with her autistic brother:

- 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.

Seven parents also referred to the vulnerability of their non-disabled children associated with the 'stigma' of being from a 'disabled family'. E1's mother explained:

He [E1] is growing up now, nevertheless, sometimes, he struggles... there are lots of people who don't understand my child [E2] when I take him out in public. They treat us as strange [mad]. I am really worried about this.

She was worried that the powerful influence of negative socio-cultural attitudes may be enough to reinforce E1's sense of being different, to undermine his sense of ordinariness in everyday social and community life and subject him to a *form of secondary experience* (Burke 2007, 12) associated with autism. G1 described his own 'secondary experience':

He made me *jjockpalida* [a slang expression used by young people to mean losing face]. Last time, we went to 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 back quickly 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.

Six of the nine children used the word '*jjockpalida*' when their autistic siblings' behaviour attracted attention in public. In these circumstances the familiarity of living

with an autistic sibling at home was thrown into sharp relief and became 'strange' (Harwood 2006). The children had however become used to the way in which their autistic siblings' behaviour was perceived as 'strange' by members of the public. The children and their autistic siblings were typically involved in various interactions with people within and outside the family on a daily basis. With their understandings of 'able' and 'disabled' society, the children reframed the behaviours of their autistic siblings as 'familiar'. In a reviewing session H1 commented:

When I knew he was autistic, it was really hard. There were lots of hard things. But now, I am used to him in daily life. I don't see it as strange, I am really wondering whether I feel it is hard... Unlike other people, I do not regard 'strange' things as strange at all because I have adjusted already.

None of the children used the word 'autism' to describe their autistic siblings, but neither did they deny their siblings' autism, reframing this as a different way of being a 'brother or sister' rather than having an 'autistic brother or sister'. For instance: 'H2 is "*jangea*" [an autistic] child. That is true, but I don't think he really looks any different to me' (H1).

This view contrasts with more traditional Korean cultural views by focusing on the 'familiarity' of his sibling's autism rather than its 'strangeness'. And while the children became used to experiences of negative attention in public, six described experiences of positive social inclusion in public settings. For example:

Interviewer: Have you and your brother been teased or experienced discrimination?
 J1: No, we have not. People say he is really cute. They normally respond to him very well.

Two of the children expressed a clear desire to encourage a wider reframing of the 'strange' as 'familiar', in an attempt to integrate understandings of autism as part of ordinary life. In the words of H1: 'I want to dramatically change people's negative thoughts and misunderstandings about autism'.

Experiencing public perceptions of autism as 'strange' was particularly challenging for the children in this study, who were acutely aware of the stereotypes associated with autism. While social acceptance and inclusion require awareness and understanding from the community (see Evans and Plumridge 2007), the children's familiarity with autism enabled them to reframe their lives as 'ordinary'.

All the children in the study used a 'medical' lens, to conceptualize autism. Their accounts referred to 'sickness' or 'illness' linked to brain abnormality, deficits of communication, and/or inappropriate behaviours. In her video diary, 7-year-old B1 said 'my brother is ill now' and later explained 'his head is not well'. For C1 autism meant that: 'you cannot communicate with others'.

Seven children believed that the limitations associated with autism could be overcome. In this way, they reframed autism as an illness from which their autistic siblings could recover. In home movies, five children focused on their autistic siblings' abilities rather than their limitations, expressing pride in their efforts and achievements, and made clear references to developing independence. H1 explained:

To be honest, people with disability are not so different... it was expected that parents should take care of disabled children until they died. So 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. 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 a long time.

The process of reframing autism in a positive way appeared to be associated with improvements in sociability and communication. J1 described his autistic brother's developing abilities as 'getting better' and expressed his own desire for his brother's 'recovery':

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... 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... 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.

These 'optimistic' accounts stand in sharp relief against a background of culturally- embedded negative public representations of disability in Korea, and helped seven of the children in this study to reframe their understanding of autism as ordinary, as having different abilities, or as curable. As a result, they believed that their autistic siblings could be included in wider society.

Discussion

Cultural beliefs about disability play an important role in determining how disability is perceived. Attitudes towards disability are deeply embedded in communities and cultures (Shakespeare 1994; Gilson and Depoy 2000; Ali et al. 2001; Rao 2006). Social barriers and prejudicial cultural images of disability cannot easily be removed by simply adopting a disability rights approach as implied by the social model of disability. The study described here found that siblings of autistic children faced '*Ijil*' (the shame of difference) created by stigmatizing attitudes to autism. These findings echo Grinker's (2007) argument that 'in Korea, autism confronts a different cultural framework' (239) and fits the profile of a condition that carries a high level of stigma. The powerful, negative, use of Korean language to describe autistic people perpetuates images of 'abnormality' and contributes to children's experiences of a 'secondary form of disability' (Burke 2004).

The implication is that the use of the social model of disability in cultures where collective family interests are valued above individual rights will not be sufficient to challenge negative public perceptions of, and attitudes towards, disability. The children in this study reframed their experiences of negative public reactions in which they risked losing *Chemyon* in order to address the dissonance between socio-cultural realities of disablism and their daily reality of 'ordinariness'. Social prejudice in wider Korean society did not prevent the children in this study from having a social life. In contrast with Euro-American and other Korean studies (see Howlin 1988; Bågenholm and Gillberg 1991; Roeyers and Mycke 1995; Lee and Kwon 2002), none of the children in the sample were prevented from participating in social activities, daily routines or social circles. One cautious conclusion drawn from this small-scale study, therefore, is that living with an autistic sibling in urban Korea is not usefully conceptualized merely in terms of restrictions. For the children in the sample, having an autistic sibling was no more, no less, than a 'natural part of life'. By successfully

reframing their negative experiences, the children demonstrated resilience and achieved effective coping skills to deal with the dominant socio-cultural attitudes to disability in general and autism in particular.

Although concepts of resilience are anchored in western social science, the notion of resilience is relevant to non-western settings (see [Crosnoe 2005](#); [Daniel 2008](#)). Consistent with other recent research ([Ungar 2008](#)), this study argues that culture has a powerful impact on the development of resilience in children living with autistic children. Despite socio-cultural values that marginalise disabled children and their families the children in this study focussed on the 'familiarity' of autism rather than its 'strangeness', leading to a sense of belonging within the wider community. In this way the children developed the capacity to adapt to the challenges presented by 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 focussed on ability and 'recovery' rather than limitation and tragedy. The children 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. Focussing positively on abilities enabled them to avoid long held negative constructions such as sins or evil deeds of ancestors ([Erickson et al. 1999](#)) and to reconstruct the consequences of being 'amenable to change' that can be negotiated to achieve inclusion in society. In contrast to other studies (see [Katbamna et al. 2000](#)), the findings illustrate that the children valued and took pride in the abilities of their autistic siblings.

Conclusion

This small-scale study focused on nine children and their families, and there is no intention of generalising from the findings. However, the study raises important questions about, and contributes to the growing literature on, the ways in which disability is constructed and deconstructed by children within different socio-cultural settings. The development of cultural resilience by the children in this study co-occurred with the assumption of responsibilities towards their autistic siblings that went beyond normative family expectations. However, we argue that it is not helpful to make a simple distinction between the 'risks' associated with children's caring responsibilities and the development of resilience. Rather, we encourage thinking that will focus on forms of support for siblings of autistic children that will nurture understanding of disability in Korea and relieve social pressures on the families of autistic children. In theoretical terms, the findings of this study suggest that the power of the social model of disability is unequally distributed across different socio-cultural settings. And we argue that the achievement of greater equality of opportunity for disabled children and their families continues to require individual expressions of aspiration and the development of resilience to overcome the barriers created by stigmatizing attitudes to disability that continue to marginalise disabled children and their families in many parts of the world.

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