

## Chapter 20

# Family Quality of Life in Several Countries: Results and Discussion of Satisfaction in Families Where There Is a Child with a Disability

Roy I. Brown, Keumja Hong, Joanne Shearer, Mian Wang,  
and Shin-yi Wang

### Introduction

This chapter is about quality of life in families where there is a child, regardless of age, with an intellectual or developmental disability. The results are from Australia, Canada, South Korea, and Taiwan and particularly involve the perceptions of the primary carers (mostly mothers) as respondents. The material has been collected from Australia and Canada, although additional findings from Taiwan and South Korea are also included. The procedure involved asking families to complete, through the primary caregiver, the *Family Quality of Life Survey*, first edition (Brown, Brown et al., 2006) across nine domains, with particular reference to family satisfaction.

The challenge for the field is that many children with disabilities are now living in the regular community. Many people support this move, because it did away with the types of institutional settings, often of vast size, which caused concern in many countries. Previously, thousands of children and adults had little opportunity to return to the community and live an integrated and inclusive life. Although this development has been critically important in the lives of a large number of people, a serious challenge arises for many families (see Turnbull, Brown, & Turnbull, 2004). How do they cope when there is a child who is severely disabled, or a child with multiple diagnosis or extreme emotional behavioral problems within the family (see Brown, MacAdam-Crisp et al., 2006)? What happens to the family, what issues arise, and how can we ensure that the vast burden of responsibility of care and support is alleviated when making our society truly inclusive, while providing the types of support services that are required? The overall aim of society, through government policy and community services, is to enable the child with a disability to function as effectively as possible, and also to enable parents and other siblings to function effectively, and wherever possible, live lives of quality (Brown & Brown,

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R.I. Brown (✉)

University of Calgary, Calgary, AB, Canada; Flinders University, Adelaide, SA, Australia  
e-mail: roybrown@telus.net

2003). Family is the environment, which enables the individual members to develop and grow effectively.

The present chapter is primarily concerned with how disability affects those in the family who are not disabled and how we can develop ways of mitigating negative effects so each member, including the person(s) with intellectual disability, can function optimally. The issue is not just a child with a disability in a family but the interaction of disability with the family members as a whole.

## Family Definitions

Families are seen in many societies as consisting of one or two parents and their children. Because of changes in social norms, a wide range of family constructs must now be taken into account, which were not seen as so relevant in the past. Families may be small or very large and wage earners may be none or several. The range and the complexity of families vary considerably and each structure brings rewards and challenges. This also applies to families where there are children with intellectual or developmental disabilities. We now recognize that there are various definitions of family, and in the research we have carried out we accept the parent's, generally the mother's, definition of how the family is constructed (see Brown & Brown, 2003, 2004).

## Family Quality of Life Survey

The *Family Quality of Life Survey* is made up of domains of family functioning (see Isaacs et al., 2007). All impact the family in some way or other, but often in different ways. The survey was completed by individual family members who responded to the questions in the survey either on their own, through a face-to-face interview, or by telephone. At the respondent's request, this sometimes included a lengthy, on occasion up to 2 h, session where the respondent wished to elaborate at length on the answers. The detailed interviews provided amplification of qualitative information provided in this chapter.

The survey begins with information about the family and the duties each member performs. It then leads into nine domains of family life. The domains in the *Family Quality of Life Survey* are

1. Health of the family
2. Financial Well-Being
3. Family Relationships
4. Support from Other People
5. Support from Disability Related Services
6. Spiritual and Cultural Beliefs
7. Career and Preparing for Careers
8. Leisure and Enjoyment of Life
9. Community and Civic Involvement

Many of the domain questions in the survey are based on Likert scales. In this chapter, we are particularly interested in the satisfaction with family quality of life in each domain. The Likert measure on this dimension (FQOL Satisfaction) uses a 5-point scale ranging from very dissatisfied to very satisfied.

The survey question, for example, from the Health domain took the following form:

All things considered, how satisfied are you with the physical health of your family as it is today?

- Very satisfied
- Satisfied
- Neither satisfied or dissatisfied
- Dissatisfied
- Very dissatisfied

The satisfaction questions from other domains take a parallel form. The results are presented in a series of figures covering satisfaction in each domain across samples in several countries. The study samples are from Australia (South Australia), Canada (British Columbia), South Korea, and Taiwan. The studies represent a continuum of exploration by the authors. We present the results in this form so that readers can see the sequence of our studies over the period of data collection and note how discussion and conclusions developed, including the variables that have come into play. We now believe these results should be considered very carefully in future studies and that outcome recommendations should be further explored and applied in policy and practice.

One of the most important aspects of Family Quality of Life is whether a family believes they have a life of quality across the nine major domains of family life. In the following figures the data reflect the highest 2 scores – that is “satisfied” and “very satisfied” combined. In the rest of this chapter, we refer to this combination as representing satisfaction. We argue that because if services are provided and family needs are met, then it is necessary that the family respondent record satisfied or very satisfied. Agency services and policymakers would presumably expect that their support and intervention contributions would lead to satisfaction. This is certainly the expectation of family members. Our aim is to measure domain satisfaction and through the qualitative addition of commentary associated with each domain isolate where needs occur, their frequency, and then how they affect family quality of life. From this we suggest ways in which families can be strengthened and increase the viability of each member including that of the individual with a disability.

## **Family Satisfaction Data from Four Countries**

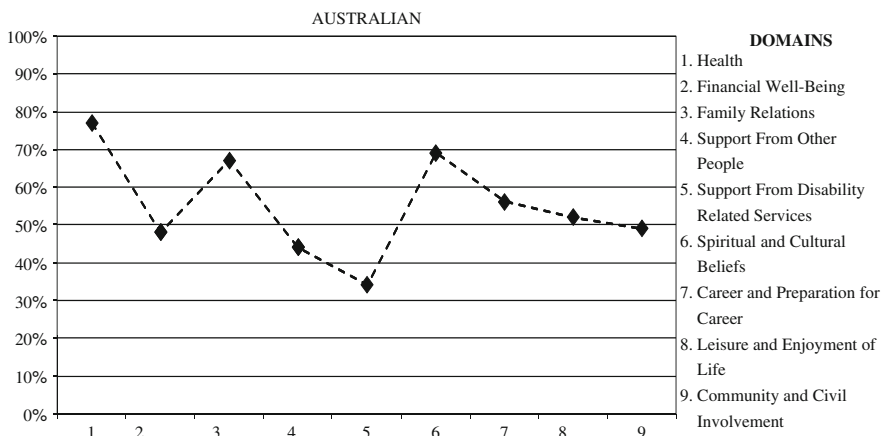
We have been fortunate to be able to collect data from four places, and this information is presented below. The data from Australia and Canada are presented in the

order in which they were collected, along with discussion. These results are then followed with data from South Korea and Taiwan.

### Australian Results

The sample families were obtained through agencies working with children with intellectual disabilities in South Australia and involved both city and rural communities. The sample, of 55 families, consisted of parents who agreed to be involved in the study. It can be regarded as a convenience sample. The children were aged between 2 and 41 years, so there is a wide age span that included children who are now adults.<sup>1</sup> The sample represents a mixed group of people. The individuals with intellectual disabilities included some with Down syndrome and a few with autism. In our initial research, these diagnostic groups were not separated, which is fairly consistent with other studies carried out in the family quality of life area (e.g., Brown, Anand, Fung, Isaacs, & Baum, 2003).

Figure 20.1 shows the pattern of responding across domains. The vast majority of families were satisfied in the domain of Family Health, and in the majority



**Fig. 20.1** Data percentage of respondents satisfied or very satisfied with family quality of life for each domain (Notes: Total Australia ( $n = 55$ ); Respondent: Mean Age = 49 years; Age Range = 32–77. Child: Mean Age = 15 years; Age Range = 2–41. The *graph line* shown in this figure has been used for reasons of clarity (differences between domains). The domains are in the order used in the Family Quality of Life Survey instrument and the sequence of domains has no social or behavioral significance.

<sup>1</sup>“Children” is the term used to cover persons of all ages who are the individuals who have been raised by adult members of the family. Unless otherwise stated these children represented a wide age range.

of instances, Family Relations were seen as satisfactory, as they were in families' Spiritual and Cultural Beliefs. Career and Preparation for Careers were just above the 50% mark in terms of satisfaction, as was Leisure and Enjoyment of Life. Families were less satisfied about the Financial Well-Being domain that fell just below the 50% level. There are other domains such as Support from Other People, as well as support from disability-related services, whether private or public, which fell below the 50% satisfaction mark. Disability-related services showed the lowest domain satisfaction level which was within the 30% range.

The domains can be divided into what might be termed:

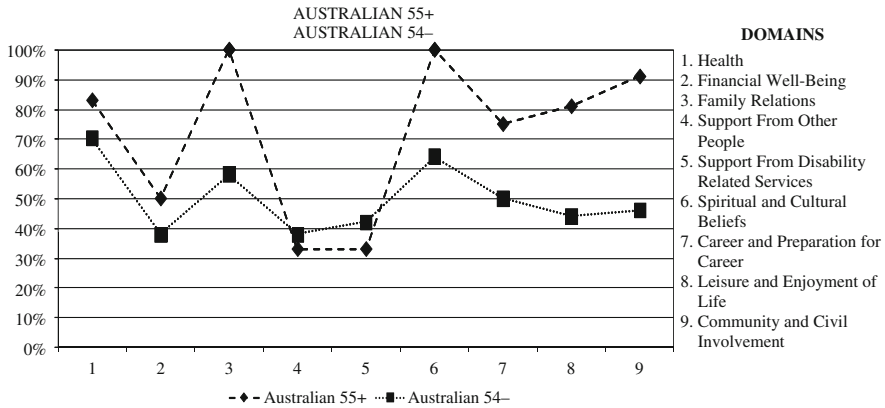
- (1) Internal family quality life, which relates to how families see themselves functioning in terms of health, family relations, and their spiritual and cultural beliefs, which were all at least at the 60% level of satisfaction, and the highest domain percentages recorded. These domains are intrinsically about internal aspects of family life, which to a large degree relate to family values and internal relationships.
- (2) External family quality of life, which relates to aspects of outside events, impacts the family somewhat differently. This includes domains, such as Financial Well-Being (i.e., essentially what the family earned from outside employment including disability allowances), support from other people in the community, and disability-related services, which were the lowest three domains in terms of satisfaction.

The differences between internal and external quality of life may be important, particularly if reflected in other studies. We are not suggesting that these two aspects are independent, for externally related domains are likely to have negative or positive impacts on family functioning. Very often internal and external domains or areas interact, e.g., a mother who is sensitive about her child's behavior may be reluctant to see neighbors, but responses from people in the community may make her more sensitive about the child's behavior which can influence family life. The internal domains are more associated with the behavior and development of families, in terms of their internal structure – their members' health, the relationships between family members and the rewards and satisfaction associated with these, and what can be termed the family's emotional, spiritual, and cultural factors.

### **Ageing and Family Satisfaction**

There is now some evidence that older families show higher levels of satisfaction across domains than younger families. [Chapter 16](#) by Jokinen and Brown in this book gives information on high levels of satisfaction in many older families consistent with the data below.

Using the Australian data, it is possible to compare satisfaction levels in aging families (parents 55 years and older) with younger ones. [Figure 20.2](#) shows higher satisfaction scores on seven of the nine domains compared with the younger parent families in the sample. The two exceptions are Support from Other People and



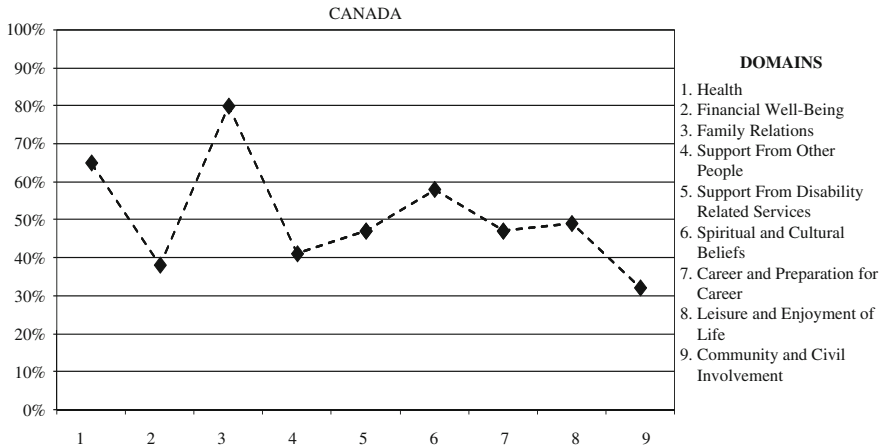
**Fig. 20.2** Data percentage of respondents satisfied or very satisfied with Family Quality of Life for each domain (Notes: Australian 55+ (*n* = 12); Parent: mean age = 63 years; Age Range = 56–77; Child: Mean Age = 26; Age Range = 14–41. Australian 54– (*n* = 27); Parent: Mean Age = 43 years; Age Range = 32–54; Child: Mean Age = 12; Age Range = 5–34. The *graph lines* shown in this figure have been used for reasons of clarity (differences between domains). The domains are in the order used in the Family Quality of Life Survey instrument and the sequence of domains has no social or behavioral significance.

Support from Disability Services, both of which are the only ones in the ageing group to fall well below the 40% levels, and the mean score is lower than in the younger group of parents.

The question that arises is whether the satisfaction levels are a result of different social norms associated with the two age groups, for as data noted in the Jokinen and Brown chapter (Chapter 16) indicates, higher happiness levels are shown among a random sample of older people from the United States’ general population. Alternatively, the difference associated with changes in the relationship between older parents and their child with disabilities may be associated with improved or more satisfying relationships, e.g., “my spouse has died and my son with a disability gives me company”, and “she (the person with a disability) now makes the beds and carries the shopping.” It seems possible that both aspects may be occurring, and in addition, older people with disabilities may in our sample be less disabled than individuals in the younger cohort.

### Canadian Results

This section presents results from Canadian research in British Columbia. The families were from a large city and surrounding areas including a major island area of the Province. The sample mainly consisted of younger families and their children. There were 51 families in this group with children aged between 2 and 11 years. The satisfaction results are shown in Fig. 20.3.



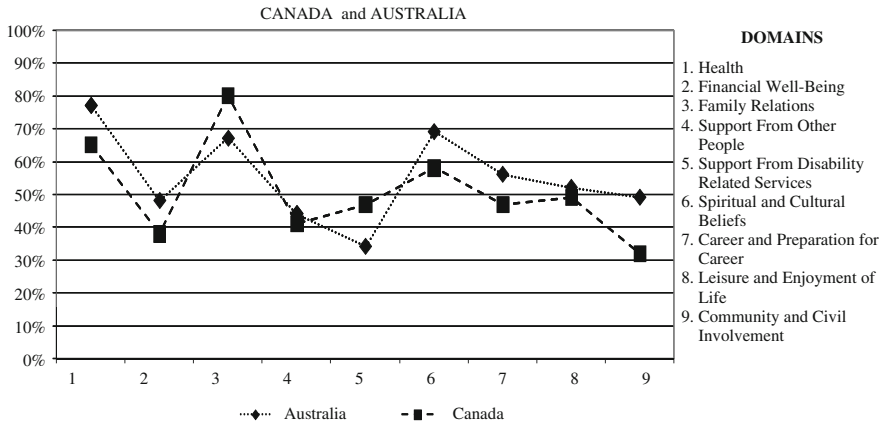
**Fig. 20.3** Data percentage of respondents satisfied or very satisfied with Family Quality of Life for each domain (Notes: Canada ( $n = 51$ ); Parent: Mean Age = 40 years; Age Range = 27–60. Child: Mean Age = 7.6 years; Age Range = 2–13. The *graph lines* shown in this figure have only been used for reasons of clarity (differences between domains). The domains are in the order used in the Family Quality of Life Survey instrument and the sequence of domains has no social or behavioral significance.

Like the Australian data, Family Relationships, Family Health, and, then, Family Spiritual and Cultural satisfaction were the most highly rated domains. Family Leisure and Enjoyment of Life, Careers and Preparing for Careers plus Financial Well-Being, Support from Other People, and Disability-Related Services were all rated below the 50% level in terms of satisfaction. In the areas of Career Development and Preparation for Careers, as well as Leisure and Enjoyment of Life, the ratings were just below 50% satisfaction, while Community and Civic Involvement was substantially low and Financial Well-Being returned the second lowest satisfaction rating.

**Australian and Canadian Comparisons**

It is interesting to show the Australian and Canadian data in one figure (see Fig. 20.4.)

These satisfaction results show very similar patterns for both the Australian and the Canadian groups. The relative lows and highs are similar. Health of the Family, Family Relationships, and Spiritual and Cultural Values show the highest domain percentages in both groups, the first two lie in the 60–80% range. Spiritual and Cultural Beliefs are above the 60% level for the Australian data, and the Canadian result is only just below. The remaining domains for Canada lie below the 50% level. Both Financial Well-Being and Support from Other People, that is those in the surrounding neighborhood and extended family (i.e., family members not living



**Fig. 20.4** Data percentage of respondents satisfied or very satisfied with Family Quality of Life for each domain (Notes: Australia ( $n = 55$ ); Respondent: Mean Age = 49 years; Age Range = 32–77; Child: Mean Age = 15 years; Age Range = 2–41. Canada ( $n = 51$ ); Respondent: Mean Age = 40 years; Age Range = 27–60; Child: Mean Age = 7.6 years; Age Range = 2–13. The graph lines shown in this figure have only been used for reasons of clarity (differences between domains). The domains are in the order used in the Family Quality of Life Survey instrument and the sequence of domains has no social or behavioral significance.

with the nuclear family), are below the 50% level and are among the lowest domain scores in both countries. Support from Disability-Related Services in terms of family is the lowest satisfaction domain in the Australian group, below 40%, while the Canadian sample lies in the 40% range. The questions arising relate to impact on the family by such services, not just the person with a disability i.e., “All things considered, how satisfied are you with disability related services your family receives?” Service to and support for the family, rather than just the individual with a disability, is discussed later.

The results from both of these samples seem reasonably consistent, and the suggestion made earlier that domains can be divided in terms of internal and external areas seems reasonable. However the types of support or intervention required, where families are low on the first set of domains, maybe very different from that required in the case of poor responses in the second set of domains. One obvious difference is that more families are satisfied on the internal set of domains while less than half are satisfied in the external set of domains. The data suggest that a portion of families face considerable internal family dissatisfaction when there are major challenges in families, namely, Family Health, Personal Family, and Relations plus the lack of satisfaction or absence of support or spiritual and cultural beliefs. In fact, where there are strong spiritual and cultural beliefs, family viability appears to remain strong.

The types of supports required are somewhat different. Support services for such families need to consider how these families can be helped further. The results



suggest a gap in service policy and support services. Generally, families are not seen by services as the major focus for such impact, and it is suggested these are areas where greater support is required. It therefore appears that we can separate out at least two types of families: (1) those who have positive and satisfactory internal family dimensions, but lacked adequate support for aspects of external family life and (2) those families who have low levels of satisfaction in both internal and external aspects of family life.

Although there is obviously variability within and between groups, it does suggest that in families with high satisfaction in what we have termed internal family domains, but with low external satisfaction, personal support needs to be provided along with direct funding, which is an economic proposition for particular families (see later). In terms of other aspects of external support, for example, the domain of Community Support including neighbors is often an area of low satisfaction, indicating a need for society to provide information and example. A number of quotes from both the Canadian and Australian records support this view, e.g., "I thought I was the only Mum who was ignored by neighbors." Other examples relate to employment, including financial earnings and career and career preparation. Careers and Preparation for Careers within the family, which includes schooling as well as tertiary education and/or employment satisfaction for children and parents, lies around the 45–56% level in samples from both countries, for example, "I had to give up my employment which involved travel for a lower paid, but local job, so I could support my wife." "I am a single mother who has had to give up my university studies as my child (with intellectual disability) takes up most of my time." The implication is that this concern is shared by around half of the families. The question is, can we identify who these are? These types of concern are also true of Leisure and Enjoyment of life, while Community and Civic Involvement is low in the Canadian data compared to Australian.

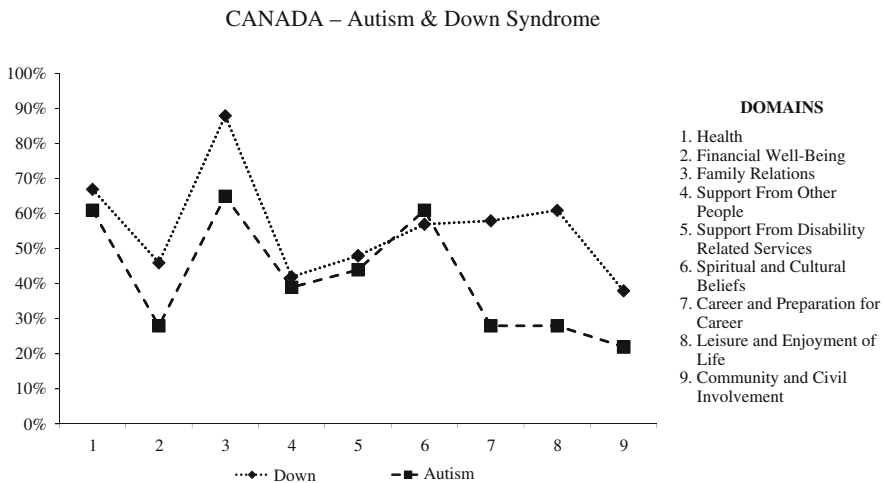
The families who have challenges in both the internal and external domains are apparently much more vulnerable and need additional and often emotional or direct personal support as illustrated by many qualitative quotations. Such families frequently show low ratings on Leisure and Enjoyment of Life. Such areas as family leisure and enjoyment of life are generally not a factor associated with priorities for policy and support services. The results here indicate major concerns with areas of outstanding need, because they relate to the ability to function effectively. Associated with this are issues of mental health, a key consideration in families where there is low satisfaction on these internal measures an aspect discussed in some detail by Esbensen, Seltzer and Greenberg (2006). They also illustrate an important principle in quality of life, namely, holism, which indicates that support in one area of functioning can affect other areas or domains in a positive fashion (see Schalock et al., 2002).

It may be asked whether these domains are related to some causal pattern? Do they reflect the holistic and interconnected nature of well-being and quality of life? One method of examining this possibility is to compare families where there are

children showing different diagnostic categories. It is possible to look at and compare the Canadian data in terms of diagnostic criteria, since two disability groups were separately selected, Down syndrome and Autism.

### Down Syndrome and Autism compared

Figure 20.5 shows a breakdown of the Canadian data into two groups: Autism and Down syndrome. The sample represents a fairly young group of families, where the children have similar mean and reasonably similar ranges in terms of age. The families were of comparable size, parental age, and economic background (see Brown, MacAdam-Crisp et al., 2006). The data now tell a new story. Although some domains in both groups show similar satisfaction percentages there are two major domains where the families with a child with Autism are much lower than in the Down syndrome group of families. These are the family members' Careers and Preparation for Careers, and their Leisure and Enjoyment of Life. Both of these domains show below 50% satisfaction within the Autism group, unlike the Down group which lies near the 60% satisfaction level, a difference which is significant. It is tempting to see these differences resulting from Autism but, as Brown et al. (2006) point out, disruptive behavior and its effects on the family is possibly the aspect which causes distress and therefore low family satisfaction. If this is the case it seems likely that other groups, such as families who have children with Fetal



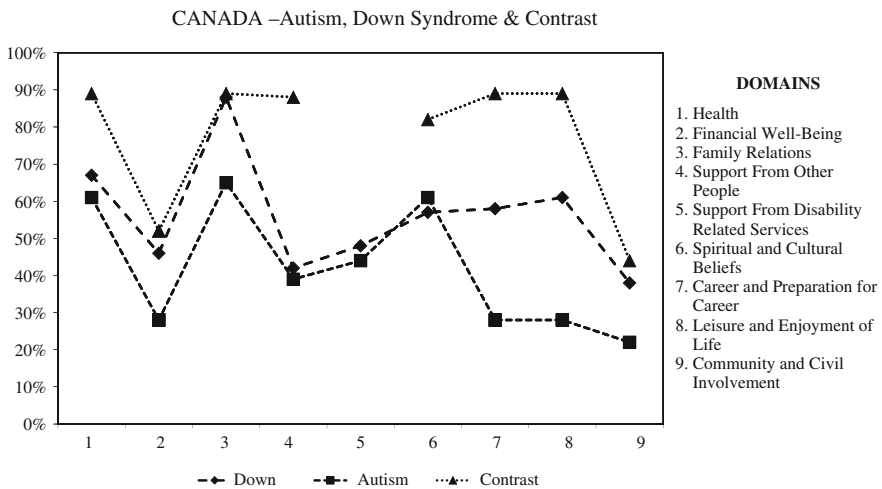
**Fig. 20.5** Data percentage of respondents satisfied or very satisfied with family quality of life for each domain (Notes: Autism ( $n = 18$ ); Mean Age: 7.78 years; Age Range: 6–13. Down ( $n = 33$ ); Mean Age: 7.55 years; Age Range: 2–12. The graph lines shown in this figure have only been used for reasons of clarity (differences between domains). The domains are in the order used in the Family Quality of Life Survey instrument and the sequence of domains has no social or behavioral significance.

Alcohol Spectrum Disorder and Prader Willi syndrome, may show similar results in terms of satisfaction. This needs to be explored in further research.

**Disability groups contrasted with families where there is no child with a disability**

The Canadian research was also designed to provide us with an opportunity to compare the two disability groups with families with a similar number of children of similar age where there is no child with a disability. There is an absence, of course, of scores for the domain, Support from Disability Services, in the last mentioned group (see Fig. 20.6). Overall there is a significant difference between the domains of the contrast group and the other two groups in favor of the former. This is particularly marked in terms of the level of satisfaction in the contrast group, which reports higher satisfaction levels in all eight domains where the comparisons could be made.

The first three domains (Health, Financial Well-Being, Family Relationships) show a similar pattern for each group but at different levels, with the Down syndrome group lying in an intermediate position above Autism but below the contrast group. It is of interest that the percentage for Family Relations is nearly as high in the Down syndrome group as in the contrast group but the Autism group is around 25% lower. The question is why should this be? Possibly, the answer lies in the nature of emotional and disruptive behavior as discussed in the previous section.



**Fig. 20.6** Data percentage of respondents satisfied or very satisfied with family quality of life for each domain (Notes: Autism ( $n = 18$ ); Mean Age: 7.78 years; Age Range: 6–13. Down ( $n = 33$ ); Mean Age: 7.55 years; Age Range: 2–12. Contrast ( $n = 18$ ) Mean Age: 6.81 years; Age Range: 4–12. The graph lines shown in this figure have only been used for reasons of clarity (differences between domains). The domains are in the order used in the Family Quality of Life Survey instrument and the sequence of domains has no social or behavioral significance).

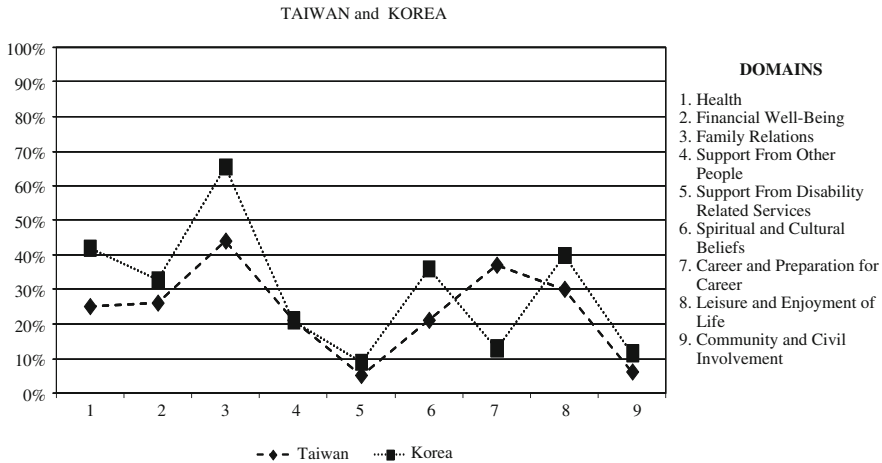
In addition, the contrast group shows a higher satisfaction level in Support from Other People which is around 50% greater when compared with the other two groups, a difference which will be commented upon later. The contrast group also has higher levels of satisfaction in the Spiritual and Cultural Beliefs domain, and the highest level of satisfaction in Careers and Preparation for Careers and Leisure and Enjoyment of Life. Community and Civic Involvement in the contrast group is higher in terms of mean score than the other two groups, but very close to that of families with a child who has Down syndrome. The results appear to show that families who do not have a child with a disability enjoy a higher perceived quality of life overall compared with the two other groups, with the Down group showing an intermediate position, lying above the Autism group. Even so, it should be noted that there are families in each group who perceived satisfaction in overall quality of life.

The survey employed in this research allows us to identify families with a relatively low satisfaction compared with others, and to identify particular domains where major challenges appear to occur. The ability to provide a fairly basic measure of domain variation and group similarity and dissimilarity represents a step toward providing information, which allows decisions to be made, their outcomes to be evaluated (See Verdugo & Schalock, 2009), and research to be focused on more specific questions and hypotheses. The results are also relevant to the clinical use of the survey (see Wang & Brown, 2009, for further elaboration). Indeed, when there are lower levels of life satisfaction in the Down syndrome group, the presence of emotional disturbance and challenging behavior appeared to be present and not necessarily in the child with Down syndrome. In one family identified through a Down Syndrome Association, we could not understand the very low overall satisfaction levels until we recognized there was also a child with Autism in the family who had marked disruptive behavior.

### ***Results from South Korea and Taiwan***

Later on data were collected on the same instrument from South Korea and Taiwan. The Taiwanese data are from a sample of families of children with developmental delay. All the children had been diagnosed as autistic and attended a hospital therapeutic program. The families lived in an urban area in Taiwan, most in a city located at the western and central part of Taiwan with a total population of over 1 million. A few of the families lived in the county nearby, and spent 30 min–1 h driving or in other transportation to the hospital. The Korean population can be described as mixed. All the children had developmental disabilities including Down syndrome, autism, and cerebral palsy. The population is diagnostically similar to that of the Australian sample.

The satisfaction results for both South Korea and Taiwan are seen in Fig. 20.7 and in several domains show lower levels of satisfaction than the Australian and Canadian data. This is particularly true of the Taiwanese results. The South Korean data are also considerably lower than Australian and Canadian data in terms of



**Fig. 20.7** Data percentage of respondents satisfied or very satisfied with Family Quality of Life for each domain (Notes: Taiwan ( $n = 83$ ) Parent: Mean age = 37.9 years; Age range = 26–58; Child: Mean age = 5.4 Age Range = Child 1–14. Korea ( $n = 81$ ); Parent: Mean age = 37.7 years; Age Range = 21–51; Child Mean Age = 8.4; Age Range = 4–18. The *graph lines* shown in this figure have only been used for reasons of clarity (differences between domains). The domains are in the order used in the Family Quality of Life Survey instrument and the sequence of domains has no social or behavioral significance.

Family Health, Support from Other People, Careers and Preparation for Careers, Leisure and Enjoyment of Life, and Community and Civic Involvement. The South Korean data show only one domain, Family Relationships, where the majority of people are satisfied with their quality of life. It is also the highest domain for satisfaction for the Taiwanese data, although that is within the 40% range. The Taiwanese data, unlike other data reported so far, shows a very low rating in support from Disability-Related Services, though not significantly different from the South Korean percentage. The other lowest areas are Support from Other People and Spiritual and Cultural beliefs. It is of concern that issues of Family Health and Financial Well-Being are reported at low satisfaction levels in the Taiwanese data.

Research in South Korea recognizes issues of children with developmental disabilities necessarily involve the whole family. However, interventions have only focused on children with disabilities, and circumstances involving the family have been overlooked (Chung, Lee, & Chung, 2003). It is also important to take into account Korean perspectives about children and disabilities if one is to understand the quality of life of Korean families. The idea that children’s disabilities result from sins committed by their parents in a previous life is a traditional and pervasive among Koreans (Yang, 1998). Therefore all problems or suffering which result from children’s disabilities are expected to be solved by their parents. It is probably because of this belief that social rights of children with disabilities and their families have developed in a passive way. As a result, social policy and social services for the

families of children with disabilities are still very restricted, even though there has been great progress in Korean social policy for people with disabilities since 2000.

It seems likely that quality of life which is perceived as relatively low in such families may be associated with society's views about disability, and then the consequent lack of appropriate social services. Parents who provide primary care, because of lack of these services even for day care, can rarely pursue a professional career or obtain employment. Also, services such as respite care, which can release parents from daily physical care tasks, are as a rule not available in Korea. Because of this, the parents execute labor-intensive care tasks for themselves with little opportunity to look after their own health. In other words there appears to be an interactive cycle, which may be associated with the prevailing value or belief system associated with disability (Brown & Brown, 2003; Keith & Schalock, 2000). It is perhaps not surprising that Korean families showed a lower level of quality of life in terms of health even though Korea has a highly developed institutional health insurance system.

In general, Asian societies are likely to be family or community-centered, so it was expected that Korean families would be relatively more satisfied with supports from other people. However, interestingly, the result showed that this expectation was not supported. Korean parents, due to their beliefs about children and disability, are inclined to conceal that they are raising children with disabilities and therefore isolate themselves from neighbors (see Lee, 2002).

One of the critical difficulties families with a disabled child experience is a financial problem. Families raising a disabled child incur extra expenses but have less time and opportunity than members of other families to pursue a career and find a job (Kim, 1997). Indeed this is not unique to South Korea and is a challenge faced by a large portion of the families reported from other countries in this chapter, along with concern that the parent, generally the mother, has more responsibilities for caring than they would like, an aspect which probably influences satisfaction levels in most if not all domains of family quality of life.

Since 2006 the South Korean government has provided financial support to families raising children with disability, which was approximately \$50 per child per month in 2008. This amount of support was insufficient to significantly reduce the financial burden on the family, and most of the families reported financial difficulties. In addition financial difficulty probably plays a significant role in limiting social service use, and this is supported by the finding that the level of support from disability-related services domain was lower than other areas. However, once again it is likely that this is an interactive issue where each domain impacts or is impacted by the other.

Taiwanese satisfaction results appear, overall, to be lower than data recorded in Australia and Canada, though reasonably similar to those from South Korea. However, it should be noted that the children were all diagnosed with Autism, the group which also showed much lower satisfaction levels across domains in the Canadian Group. This is of particular interest because some work by Chou and Schalock (2009), using quality of life data from Taiwan, notes that average quality of life scores for "social belong/community integration" among all Taiwanese residents from three residential models were lower than the residents in the studies

conducted by Schalock and Keith (1993) in the United States and Otrebski (2000) in Poland. Chou and Schalock's conclusion is that policy changes are desirable so that quality of life can be taken into account in service delivery. Their data applied to persons with intellectual disabilities, but they also suggest that expectations for quality of life were easily satisfied for many individuals.

Research in Canada Brown, Bayer & Brown (1992) suggests that introducing a quality of life approach raises expectation and helps individuals focus on raising their own quality of life – one of the reasons that an intervention model needs to be replaced by a support model encouraging personal choice and decision making, which is then supported through services and community action. The present chapter suggests that the same may well apply to the families of children with intellectual disabilities. This also seems consistent with the Taiwanese family quality of life research. Further exploration is necessary, as is the case with the South Korean group. For example, the lowest score in support from Disability-Related Services may be associated with insufficient welfare support for the participants. Further, the major act providing welfare support to people with disability in Taiwan, Welfare Act for People with Disability was established in 1990 with a focus on the provision of medical, educational, and vocational supports to the persons older than 6 years with disabilities. Children younger than 6-year old and the families of people with disability were not seen as a central focus of the welfare system. Most of the participants in the Taiwanese study were the families of young children with Autism that tend to benefit least from the current welfare system. Furthermore, the low scores in Support from Disability Services, Support from Other People and Spiritual Culture dimensions may be explained by the negative views toward disabilities in society and this, too, appears consistent with the South Korean data where having a child with Autism can be viewed as a punishment from God or through wrongdoing of the family members. Families may isolate themselves and avoid seeking supports from the government and others in the community, including religious organizations, in order to avoid being seen as of “bad family.” However, the connection between the core family members can become stronger, because sharing the responsibilities for taking care of the child with disability within the family is taken for granted and honored in Taiwanese culture. In terms of the Taiwanese low scores in Family Health and Financial Well-Being, it is not clear if having a child with disability increases the anxiety toward Family Health and Financial Well-Being. Most families in Taiwan emphasize the importance of physical health and saving money. A sense of crisis toward physical health and saving money can arise when a family has a child with disability. Insufficient support and the nature of support from the government, the cost spent on the child with a disability by the family, and the income loss caused by caring for the child may prevent the family from saving money both for the future needs of the child with a disability and for other members of the family in the future, and thereby increasing their dissatisfaction.

Overall it would appear that the two sets of data from South Korea and Taiwan show much lower satisfaction response rates compared with either the overall Canadian or Australian results. The South Korean sample is a mixed sample and, like the Taiwanese data, underscores the importance and relatively high level of

satisfaction with family relations. However, the Taiwanese data, which is based on families where there is a child with Autism, have some similarities with the Autism sample from Canada. In both cases where there is a child with Autism, Leisure and Enjoyment of Life falls below the 40% level. This must be regarded with concern and should result in changes to policy and support.

## Discussion

It is important to remind the reader that the questions in this survey are directed toward issues about the family, not just the person with a disability. The responses represent perceptions of the respondent. Researchers (e.g., Andrews, 1974) have recognized for a long time that perceptions are a major driving force of human behavior, that is, what is perceived and believed affects how the individual or, in this case family members behave. This includes how a family is affected by its belief and value system, the nature of disability services, whether they are private or public; health and the satisfaction of health in the family, and so on. This means any and all members of the family may have experiences that cause the person filling in the survey to rate the family higher or lower on the 5-point satisfaction scale. In the Canadian and Australian data where qualitative information was recorded in addition to ratings, it was clear, for example, that though the respondent recognized that direct support had often been given to the person with a disability, no mention was made of services supporting the family needs resulting from disability. This is one possible explanation for the relatively low ratings on the support from Disability-Related Services domain in all four countries. In this context, there are often pressing challenges, for the disability of one member of the family negatively influences the behavior or resources of the family as a whole, for example, when a mother has to give up her job to look after her child.

It is also important to stress that the survey is an attempt to measure individual aspects of life through the domains, as well as document interaction between domains. It is likely that the level of satisfaction in one particular domain influences and is influenced by other domain values and experiences. Factors, such as behavioral disruption, can become the focus of concern in some families. In other words, this survey approach provides an opportunity to look at all aspects of life and their integration.

The holistic hypothesis needs further investigation. It seems plausible and underscores the possibility that intervention and support in one key area is likely, because of the holistic nature of human behavior, to improve other aspects of family functioning and therefore overall family satisfaction. Key areas differ to some extent from family to family, or over time in the same family, arguing for an individual approach to support. We have also noted that there appeared to be families where internal aspects of family life were positive and the challenges largely arose from outside the family, e.g., community reaction, lack of support, and lack of appropriate respite when required. These challenges necessitate careful and considered observation, reflection, and flexibility on the part of policy and service personnel.



Additionally, combining intervention and/or support in more than one domain, e.g., Family Health and support for the family in terms of enjoyment of life (Leisure and Recreation or Career Preparation) is likely to have greater and possibly wide-ranging effects on a family's overall satisfaction and quality of life. This would need much close collaboration between different service groups and would require much greater coordination of policy between different departments and agencies. If such arguments are correct such an approach: (a) requires an accent on service and support across agencies; and (b) should have long-term economic savings, since such coordinated intervention might be expected to have holistic benefits, such as an increase in family overall health and economic viability. However, as stressed by Brown and Brown (2009), such intervention and coordination should critically involve the family perception of needs and choices. It is important to consider how domains may link together. The lowest domains, in terms of satisfaction, are Financial Well-Being, Support from Other People, and Support from Disability Services so the interplay between these domains warrants further examination. In addition to these domains, in some families, particularly those where there is behavioral disturbance as in the Autism group, low levels of satisfaction are returned for Careers and Preparation for Careers and in overall Enjoyment of Life. Also, Family Relationships appear lower in the families where there is Autism compared with both the Down and the contrast group. The challenge may not be Autism per se, but disruptive behavior which influences the family as a whole. This suggests challenging behavior by the individual, which can sometimes be severe, such as screaming and rocking behavior and aggressive outburst toward others, is a highly relevant factor, and this is consistent with a study carried out by Brown in Scotland and to be reported in the near future. It is important to put the notion of disruptive behavior into context. In some of these families isolation due to separation of the parents often appears to exacerbate the situation. There are exceptions to this where breakdown between the parents resulted in an improved quality of life according to a few qualitative comments, e.g., "life became better when he left."

Sometimes some of these behaviors occur in the Down syndrome group. However, there seems much less dissatisfaction around a number of the domains where Down syndrome families are concerned. Where there is challenging and disruptive behavior there appears to be greater negative family impact on quality of life for all of the members of the family. It seems likely that this is why such families do not see the disability and support services responding to their needs. What then are these concerns across domains in such families? They include:

- Lack of short-term respite care when required and necessary for acceptable family life
- Longer term respite where a child has major behavior disturbance
- Lack of necessary information and how to get existing information about services and supports
- Challenging behavior which is continuously disruptive to all family members
- Lack of relief for parents who may have had no vacations over many years
- Parents unable to have time for themselves or together with their spouse or partner

- The inability of children or adults to study at home in a suitable atmosphere
- Instances where employment has to change or to terminate in order that one or both parents can provide better support for their child in the home.
- Financial impact on each member of the family.
- The above and particular challenges associated with single-parent status

Siblings may be impacted in terms of studying, and having friends to their home. Further, it may be difficult to invite guests or have neighbors over because of major behavioral disturbance. Quite frequently there is a lack of desired support from neighbors and community. This occurs in both the Down syndrome and Autism groups and also other developmental disabilities, although the lack of support appears much higher where multiple disability occurs, and includes lack of appropriate support from community agencies such as religious organizations. The result is that families, and therefore people with the disabilities, are then effectively cut off from necessary support and community interaction. This is a major form of exclusion and raises important questions when many agencies and individuals go to some length to advocate inclusive policies, though to address this community knowledge and experience in handling such needs are relevant. Although such occurrences are not universal, they appear frequently in the records of our data. There is a need to carefully examine the practical impacts of exclusion and what this entails (see Brown and Brown, 2003).

In some instances a parent has indicated that they feel ignored by neighbors, but occasionally concede that this may sometimes come from their own concerns about what neighbors might think. There is a lack of consistency of service, and among those parents who are older, concerns for adequate services after they themselves cannot cope, or will have died. On top of this, lack of knowledge about services, and the inability to get needs met remain major issues from primary carers whether they are parents or siblings (see also [Chapter 16](#) by Jokinen and Brown, this volume for further details).

It is important in further studies in the disability field to ensure there is a comparison age group without disabilities (compare Brown, MacAdam-Crisp et al., 2006). The results underscore the importance of comparative data from the general community. This may be relevant, not only in terms of differences between countries, but also in terms of comparisons across cultures, and may be used as a yardstick or, as in the cases described here, to pinpoint some of the issues which are of major concern and particularly impact families across the lifespan where a child with a disability is involved. In all the studies described, the support from disability-related services are regarded as among the lowest in terms of satisfaction, whether that is from the Australian data including older families, Canadian data involving young families with Down or the Autism groups, with the greatest concerns being stated in those families where there is a child with challenging behavior. The interpretation of this is important. Disability-related services do provide considerable support for the child with a disability, yet many families remain highly vulnerable and require additional assistance that would enable the whole family to function more effectively economically, socially, and emotionally. The areas of

concern for family members include challenges in education and employment. Both these challenges lower family economic status particularly when behavioral and emotional disturbance are involved. Behavioral and emotional disturbance reduce the family's ability to work and study, and has some wider and damaging effects on siblings who live in such families. It is suggested that both on economic and health grounds, it would be prudent for disability-related services and policymakers to provide more direct family support than currently is the case, and that support needs to be specific and targeted to families where there are particularly low satisfaction ratings. Such support is likely to positively influence family relations and resilience, through reduction in relentless stress, which often results in individuals experiencing fatigue, should positively influence overall family quality of life. Such measures underscore the changing focus of studies which are moving from a deficit model to the promotion of well-being and quality of life (Ylvén, Björck-Åkesson, & Granlund, 2006).

A guiding principle in this context comes from quality of life research which underscores the importance of choice by family members (For details see Brown & Brown, 2009), which enables families to feel in charge of their life situation and helps to stabilize family units. Importantly, from a government policy point of view, this should, in the long run, result in reduced economic need and also promote quality of health for the family as a whole.

The above means a fundamental change in how we set policy, administer disability services, and then carry out practices at the managerial and frontline levels. It also requires changes to the way we educate personnel. An understanding of the interaction of the holistic nature of lifestyle among families with children with disabilities, and the major causes of family disruption, are therefore critically important.

The Family Quality of Life Survey seems sensitive to, and can pick up cultural and local community differences. However, such aspects need much further examination. This should not cause a delay in providing family supports, for the evidence across our samples indicates many similar results and these are largely consistent with that, for example, of Zuna, Turnbull, and Summers (2009) and is also reflected in the papers by Werner, Edwards, and Baum (2009), findings supported by the work of Wilgosh and Scorgie (2006)

### *A Word of Caution*

There are a number of families who are satisfied across the domains of family quality of life, although in most instances in this chapter, those who record satisfaction may still have important needs at a family level. Cummins' (2001b) research on individuals with intellectual disabilities and their satisfaction levels suggests that a number may indicate that aspects of the child's life are satisfactory, when in fact there are major needs and concerns. This may also apply to family situations. Such families may have less apparent needs or may be reluctant to expose people outside their family circle to their predicament. However, it seems possible that family respondents may reflect family issues more accurately than when an individual is

refereeing to their own satisfaction (see Brown, Schalock, & Brown, 2009). Further it seems likely that the populations in the present studies represent families who have the time and interest to participate in the FQOL survey. This suggests that families with greater challenges may not be appropriately represented. However, it seems possible that more disabled samples were obtained in the Taiwanese and South Korean studies, but further exploration will be necessary to determine whether this is in fact correct. For example, the Taiwanese findings came from a specific agency and are believed to be representative of that agency's families having a child with autism. Because they benefited little from general education or had been rejected by general childcare service most were brought to the hospital by the families for further treatment. Furthermore, the families in the sample are more likely to represent the families with limited resources who could not get sufficient supports or needed public funding to pay for the intervention for their child. The intervention program at the hospital was funded by the national health insurance of the government. It is also noted that families varied considerably, and it is likely that families also vary over time. It is critically important that family behavior is monitored on a regular basis. For example, the ability to access family quality of life, even on the short version of the survey (Brown et al., 2006, website), on at least a yearly or biannual basis may be important. Furthermore, there should be a means of noting when family circumstances are believed to change, and particular attention needs to be given to indicators provided by parents or other primary carers. Change in a family's life in one domain is likely to affect other domains.

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## References

- Andrews, F. M. (1974). Social indicators of perceived life quality. *Social Indicators Research*, *1*, 279–299.
- Brown, I., Anand., S., Fung, W., Isaacs, B., & Baum, N. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities*, *15*, 207–230.
- Brown, I., & Brown, R. (2004). Concept for beginning study in family quality of life. In A. Turnbull, I. Brown, & R. Turnbull (Eds.), *Families and people with mental retardation and*

- quality of life: International perspectives* (pp. 25–47). Washington, DC: American Association on Mental Retardation.
- Brown, I., & Brown, R. I. (2003). *Quality of Life and Disability: An Approach for Community Practitioners*. London, UK: Jessica Kingsley.
- Brown, I., & Brown, R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 10–17.
- Brown, I., Brown, R. I., Baum, N. T., Isaacs, B. J., Meyerscough, T., Neikrug, S., et al. (2006). *Family Quality of Life Survey: Main Caregivers of People with Intellectual or Developmental Disabilities*. Toronto: Surrey Place Centre.
- Brown, R. I., Bayer, M. B., & Brown, P. M. (1992). *Empowerment and developmental handicaps: Choices and quality of life*. Toronto: Captus.
- Brown, R. I., MacAdam-Crisp, J., Wang, M., & Iarocci, G. (2006). Family quality of life where there is a child with a developmental disability? *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 238–245.
- Brown, R. I., Schalock, R. L., & Brown, I. (2009). Quality of life: Its application to persons with intellectual disabilities and their families – introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities*, 6(1), 2–6.
- Chou, Y.-C., & Schalock, R. (2009). Survey outcomes and cross-national comparisons of quality of life with respect to people with intellectual disabilities in Taiwan. *Journal of Policy and Practice in Intellectual Disabilities. Intellectual and Developmental Disability*, 6(1), 6–9.
- Chung, Y., Lee, S., & Chung, B. (2003). *Children with developmental disability and family welfare*. Seoul: Hyunhaksa.
- Cummins, R. A. (2001b). The subjective wellbeing of people caring for a family member with a severe disability at home: A review. *Journal of Intellectual and Developmental Disability*, 26(1), 88–100.
- Esbensen, A. J., Seltzer, M. M., & Greenberg, J. S. (2006). Depressive symptoms of adults with mild to moderate intellectual disability and their relation to maternal well-being. *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 229–237.
- Isaacs, B. J., Brown, I., Brown, R. I., Baum, N., Myerscough, T., Neikrug, S., et al. (2007). The international family quality of life project: Goals and description of a survey tool. *Journal of Policy and Practice in Intellectual Disabilities*, 4(3), 177–185.
- Keith, K. D., & Schalock, R. L. (Eds.). (2000). *Cross-cultural perspectives on quality of life*. Washington, DC: American Association on Mental Retardation.
- Kim, N. (1997). *Social work intervention model for mothers of children with auditory impairment*. Busan: Busan University.
- Lee, H. (2002). Parenting social network for the children with developmental disabilities. *Korean Journal of Special Education*, 37(3), 57–74.
- Otrebski, W. (2000). Quality of life of people with mental retardation living in two different environments. In K. D. Keith & R. L. Schalock (Eds.), *Cross-cultural perspectives on quality of life* (pp. 83–92). Washington, DC: American.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., et al. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40, 457–470.
- Schalock, R. L., & Keith, K. D. (1993). *Quality of Life Questionnaire*. Worthington, OH: IDS Publishing.
- Turnbull, A., Brown, I., & Turnbull, R. (Eds.). (2004). *Families and people with mental retardation and quality of life: International perspectives*. Washington, DC: American Association on Mental Retardation.
- Verdugo, M. A., & Schalock, R. L. (2009). Quality of life: From concept to future applications in the field of intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 62–64.

- Wang, M., & Brown, R. (2009). Family quality of life: A framework for policy and social service provisions to support families of children with disabilities. *Journal of Family Social Work, 12*, 144–167.
- Wilgosh, L., & Scorgie, K. (2006). Theoretical model for conceptualizing cross-cultural applications and intervention strategies for parents of children with disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 3*(4), 211–218.
- Werner, S., Edwards, M., & Baum, N. T. (2009). Family quality of life before and after out-of-home placement of a family member with an intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities, 6*, 32–39.
- Yang, O. (1998). Social stigma on people with mental disorder. *The Korean Journal of Social Welfare, 35*, 231–260.
- Ylvén, R., Björck-Åkesson, E., & Granlund, M. (2006). Literature review of positive functioning in families with children with a disability. *Journal of Policy and Practice in Intellectual Disabilities, 3*(4), 253–270.
- Zuna, N. I., Turnbull, A., & Summers, J. A. (2009). Family quality of life: Moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities, 6*, 24–31.