

**School of Psychology**

**Perceived Effect of Disability on Adolescent Siblings of  
Children with an Intellectual Disability: Development of a  
Measure and Pilot Intervention**

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**This thesis is presented for the Degree of  
Doctor of Philosophy  
of  
Curtin University of Technology**

**August 2005**

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*Declaration*

## *Acknowledgements*

It is wonderful to be at the point of acknowledging all of the people and organisations who have provided me with valuable support, throughout the completion of this thesis.

First, Professor David Hay guided me from my very first ideas, through to the development of the research project as a whole. Associate Professor Clare Roberts for providing her valuable expertise and support particularly through the final stages of the write-up. Dr Robert Kane who provided extensive statistical support. Dr Lyndall Steed who read through the thesis before submission. Staff within the School of Psychology (Maureen Bell, Lyn Dawson, Robyn Taylor, Jeanette Vaughan, Paul Penley, Ian Case) who patiently assisted me with many practicalities over the course of my PhD. Associate Professor Jan Piek and Dr Ros Morrow for encouraging me along the way. Thank you also to ReCap for providing additional funding for this research. Monica Bragg and Sheona Stone, for your assistance following up families to increase participant numbers. Melinda Jeffs for assisting with recruiting participants through the Stepping Stones program and much needed emotional support. Simone Jeavons, thank you for your expertise with the focus groups and for being there for me. Marianne Poller for your assistance with some of the finer details of the thesis and for instilling the confidence in me that I could do it. Melinda Andrews and Peta Prindiville for assisting with other aspects of the focus groups and supporting me along the

way. Thank you to all the other PhD students for your support along the way.

A big thank you to the Disability Services Commission for assisting me with identifying potential participants and for providing funding for the second study of my research. Mairead McCoy who encouraged me to think about the wider needs of siblings and how to provide the best support for families. To Lisa Studman and Wendy Britten for co-facilitating the sibling program. It was a pleasure to work with you and I have learnt a lot from you both.

Thank you to the TVW Child Health Institute for Research, Activ Foundation, IdEntity WA, the Kalparrin Centre and the Down Syndrome Association of Western Australia who assisted with recruitment of participants. Thank you to all of the families that participated throughout the various stages of this research. I was honoured that you chose to share your personal experiences with me. Your participation has facilitated a wider interest of sibling needs in our community and helped many other families.

Thank you to my parents, Luci and John who raised me to always aim high. My brother Jason, who motivated me (and made me laugh) along the way. My partner Stuart, whose loving support got me through some of the hardest stages of the process. To all my other friends and family for supporting me and inspiring me to succeed. Finally, I can now spend much needed quality time with you all.

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## *Abstract*

The effects of disability on individuals, their parents and their family as a whole have been extensively researched. However, the specific effects on siblings have not been given adequate attention by mainstream society until recently. Consequently, few services have been available for siblings in our community. Of the research that has explored sibling needs, most have relied on parental reports or used measures developed for alternate populations measuring more general variables such as psychopathology. This research project is concerned with the development of a self-report measure of *Perceived Effect of Disability* for teenage siblings (12 -17 years) of children with an intellectual disability and the development and pilot of an intervention that aimed to assist the positive adjustment of teenage siblings.

The development of the measure involved three stages. First, an extensive item pool was constructed from past literature with 150 potential items identified. To ensure the validity of the item pool for siblings themselves, a sample of 24 teenage siblings rated the importance of the items and subscales. This reduced the number of items. Next, focus groups were run with an alternate sample of 41 teenage siblings for further evidence that all pertinent issues were included and to explore items identified as having low importance in Stage 1. The last stage involved testing the measure's psychometric properties with a further 80 siblings. Exploratory factor analyses were conducted to determine the measure's underlying factor structure. Results identified four factors underlying the measure, *Positive*

*Influence of Disability, Family Differences, Worry About What Others Think* and *Lack of Time With Others*, all of which exhibited high internal consistency and test-retest reliability over a six-week period. The final measure included 40 items and included two parts, the impact on family life and the impact on social life for siblings.

The issues identified through the development of the Perceived Effect of Disability measure were then used to develop a pilot intervention that aimed to assist the positive adjustment of teenage siblings. The result was a 6-week program, consisting of 90-minute groups covering *Sharing My Story, Exploring Differences and Disabilities, Exploring and Communicating Feelings, Coping Skills I, Coping Skills II* and *Finding Meaning*. The impact of the program was piloted with two groups, consisting of 16 teenage siblings (aged 12-17 years). A matched comparison sample was also used to determine if the intervention resulted in improved perceptions of the effect of disability on siblings using the Perceived Effect of Disability (PED) subscales. There was no significant interaction between time and group on any of the PED subscales. A main effect was found for time on the *Lack of Time With Others* subscale only. The non-significant time x group interaction, however, indicates that the main effect of time on *Lack of Time With Others* scores applied to both groups. There was no significant change in family functioning or self-esteem from pre to post-test for the intervention group. However, extensive qualitative data provided strong support for the importance of such an intervention for this unique group of individuals in our community.

## *Chapter 1: Introduction and Overview*

### **1.1 Introduction**

Disability does not just impact on the individual, but family members as well. Many researchers have recognized this, and developed services for parents to aid family adjustment. However, services for siblings of children with disabilities are scarce even though the sibling relationship is typically the longest-lasting relationship in one's life (South Australian Sibling Project, 2000). Siblings of children with disabilities may grow up in a stressful environment with many responsibilities, and may not have the coping skills to deal with their experiences. While, it is well known that adolescence is typically a time of transition and personal challenge (e.g., Erikson, 1950; Havighurst, 1974), few researchers have focused on teenage siblings. Research has shown that siblings of children with special needs experience unique challenges in their lives with varying negative and positive effects (Nesa, 1999). Furthermore, the impact on siblings occurs throughout their life span and often they are left as the primary carers for their sibling with a disability when their parents are no longer able to care for them (Strohm, 2001).

The present thesis comprises two main studies:

Study 1-        The Development of a Measure of *Perceived Effect of Disability*  
                         on Teenage Siblings

## Study 2 - The Development and Pilot of an Intervention to Assist the Positive Adjustment of Siblings

This chapter summarises both studies. This thesis describes each study independently before bringing together the overall summary and conclusions of both studies in Chapter 10.

### 1.2 Study 1: Measure Development

To date there has been only two published scales designed to measure the effect of disability on siblings of children with a disability, the *Sibling Problems Questionnaire* (McHale, Sloan, & Simeonsson, 1986) and the *Sibling Statement Scale* (Wilson, Blacher, & Baker, 1989). Furthermore few unpublished measures exist. In all cases, the methodology used to develop these measures has been unclear and the psychometric properties of these measures have not been reported. If future research is to move forward, a reliable and valid measure of the effect of disability on siblings is required.

Study 1 involved the development of the Perceived Effect of Disability measure to assess the impact of disability on siblings' family and social lives. The major aim for the development of the measure was that it be based on what siblings themselves perceive the effect of having a brother or sister with a disability has on them. The measure was developed in three stages that combined a collection of both qualitative and quantitative information from

older teenage siblings in order to produce the most reliable and valid measure possible.

Given the differences in effects of disability found for siblings at various developmental stages (e.g., Lobato, 1993), it was believed that a measure should initially concentrate on a specific group of siblings. Teenage siblings who were older than their brother or sister with an intellectual disability were thus chosen for the study as little research has concentrated on this area.

The three stages were as follows:

Stage 1: The development of an item pool and expert content validation of the item pool.

Stage 2: The collection of qualitative data on the validity and salience of items using focus groups, to ensure the item pool covered issues that were important for siblings.

Stage 3: Testing the internal consistency, test-retest reliability and factor structure of the measure.

Chapter 2 will review past literature exploring the needs of siblings of children with special needs, while the methodologies and results of each of the three stages will be discussed in Chapters 3-6.

### **1.3 Study 2: Pilot Intervention**

Study 2 was concerned with the development and pilot of an innovative intervention to assist the positive adjustment of teenage siblings of children with an intellectual disability. Information gained from focus groups in Study 1, along with recent literature, provided an outline for the intervention. Few services have been developed for siblings of children with an intellectual disability. The literature reviewed for this study indicates that no services had been specifically designed for teenagers. Hence teenagers were the focus of the second study.

The roles siblings play in their brother or sisters' health, happiness and community life are vital. Kate Strohm from South Australian Sibling Project (now Siblings Australia Inc.) (2000, p. 3) argues that "if children have their feelings validated and needs met, they are much more likely to continue to be involved in their brother or sister's life, and be able to supplement available social services". This is supported by the Family Systems perspective, which emphasises the reciprocal relationships between a family member with special needs and overall family structure and functioning (Patterson & Garwick, 1994). Therefore, identifying the needs of siblings and assisting their overall adjustment will not only help their development, but also indirectly help their whole family.

The intervention was based on the Double ABCX model of Family Adaptation, an empirically validated model that aims to predict family functioning and has

been successfully applied to families of children with an illness/disability (McCubbin & Patterson, 1983; Orr, Cameron, & Day, 1991). The impact of the intervention was then evaluated in a controlled trial with two groups of teenage siblings of children with an intellectual disability. A matched comparison group was used to determine if changes in participants' scores on the Perceived Effect of Disability measure were associated with the intervention or other factors. Quantitative and qualitative data were then analysed and the intervention refined.

Past literature focusing on interventions developed for siblings will be reviewed in Chapter 7. The development and evaluation of this intervention is then described over Chapters 8 and 9. Finally, Chapter 10 discusses the results of both studies.

## *Chapter 2: The Perceived Effect of Disability on Siblings*

### **2.1 Introduction**

Disability is a significant issue in the world today. The Australian Institute of Health and Welfare reported that 503,000 individuals in Australia had an intellectual disability in 1998 (AIHW, 2003). In Western Australia alone there were approximately 157,300 people with an intellectual disability at this time (ABS, 1999). However, disability does not just impact on the individual, but also on immediate and extended family members as well as the community as a whole. Until recently the majority of research focused solely on the parents of the child with an intellectual disability or the family as a whole. The specific effects on siblings have only been given adequate attention recently. This is surprising given that the sibling relationship is typically the longest-lasting relationship in one's life (South Australian Sibling Project, 2000).

Many studies exploring the effects on siblings have focused on whether siblings have been "positively" or "negatively" affected by having a brother or sister with special needs. While many argue that there are "positive" effects of having a brother or sister with a disability (e.g., McConachie & Domb, 1981; Miller, 1974), others have reported "negative" effects, (e.g., Friedrich & Friedrich, 1981). Some of the positive effects on siblings include: increased understanding, tolerance and compassion (Grossman, 1972); while increased anxiety (Wasserman, 1983), behavioural problems (Tritt & Esses, 1988) and

caretaking responsibilities (Farber, 1960) have been reported as negative effects for siblings. In other cases researchers have reported a balance of both positive and negative influences that siblings perceive as a result of being a brother or sister of a child with a special needs (e.g., Furman & Buhrmester, 1985; Leonard, 1997). The main limitation of most of this research is that the results are largely based on parental reports rather than those of siblings themselves. To address this problem, this study aims to explore the effect of disability from the perspective of siblings themselves and diverge from past practices by developing a self-report measure for siblings. No research to date has utilised or developed a measure based on quantitative and qualitative data from siblings themselves.

Study 1 presents the development of a new measure of Perceived Effect of Disability which will allow future research to more accurately explore the variables that influence the effect of disability on siblings and evaluate the effectiveness of interventions developed for this population. In the process this measure provides up-to-date information on how siblings in our community believe having a brother or sister with a disability has affected their lives.

In this chapter the perceived effect of disability on teenage siblings of children with an intellectual disability is examined. Of particular interest is the findings of previous research conducted in this area, which guide the aims, and rationale of the present study.

## 2.2 Existing Measures for Siblings of Children with Special Needs

The majority of past research exploring the effects of disability on siblings has relied on parental reports or measures developed for alternate populations. Only two published self-report scales could be found which are designed to measure the effect of disability on siblings of children with a disability. These are the *Sibling Problems Questionnaire* (McHale et al., 1986) and the *Sibling Statement Scale* (Wilson et al., 1989). These measures will be reviewed along with other unpublished measures.

The Sibling Problems Questionnaire (McHale et al., 1986) consists of 36 statements regarding the sibling relationship. The questionnaire is a self-report measure for siblings aged 6-15 years. The statements are answered in a dichotomous yes/ no manner. The statements are sorted into nine categories representing areas in their lives where siblings may face challenges: concerns about the handicapped child's future, feelings of rejection toward the sibling, perceptions of parental favouritism towards the sibling, positive reactions towards the handicapped child by peers, positive reactions by parents, the degree to which the child believes he/she could cope with the sibling's disorder, the perception of the sibling as a burden, self-doubts experienced by the child and feelings of hyperresponsibility.

There are four items in each category, and thus scores vary between 0 and 4 for each section. The questionnaire is based on a measure originally developed by Taylor in 1974 (cited in McHale et al.). Society's attitudes towards people with a disability have changed significantly over the past 30

years, as evidenced by the philosophy of Normalisation, Social Role Valorisation and new service delivery strategies (Carnaby, 1999; Race, 1999; Wolfensberger, 1998). Thus, this measure no longer represents what life is like for siblings today. For example, the word "retarded" is used throughout the questionnaire and an item specifically refers to the possibility of the sibling living in an institution later in life. Apart from an earlier study conducted by the present researcher (Nesa, 1999) using a modified version of the Siblings Problem Questionnaire (for example, the word "retarded" was replaced with "brother/sister with a disability"), only one other research paper that reported using this measure could be found (Bischoff & Tingstrom, 1991). The original authors did not report the psychometric properties of the measure. However, Nesa (1999) found the internal consistency of the measure to be .79 (using Kruder-Richardson 20). No other information on reliability and validity is available.

Wilson et al. (1989) conducted research using a measure they developed titled the *Sibling Statement Scale*. This scale consists of 13 statements used in an interview format with siblings. Siblings are told prior to the interview that they are going to be read a series of statements made by other siblings and then asked to indicate how similar they are to the child who made that statement. The authors report mean scores for each item from the siblings' responses in their sample and used the measure with older siblings of children with disabilities aged 9 to 13 years. The measure has been referred to by past studies, for example Adams (2000) reported using a modified

version of this scale in a research project looking at older siblings of children with language delays. However, similar to the above measure, no psychometric properties were reported by the authors and it is unclear how the items were developed.

The *Sibling Impact Questionnaire* (reported in Eisenberg, Baker, & Blacher's 1998 study) is similar to the Sibling Statement Scale though it is unpublished. There are 40 statements, which cover four "impact domains" – Positive, Family, Social/Peer and Future and are rated on a 6-point scale (which the authors later reduced to a 2-point scale) by siblings. Siblings completing the measure in Eisenberg et al.'s study were from a very large age-range (9 - 20 years). The authors report that the Cronbach's alpha for the domain scores for their sample ranged from .68 to .84. Fay and Barker-Collo (2003) have reportedly used the measure in research exploring sibling relationships and behaviours after childhood traumatic brain injury. However, no further psychometric properties were reported by either group of authors. The authors have not reported the methods used to develop the measure and the "impact domains" have not been confirmed through factor analyses.

Siegel and Silverstein (1994) developed six questionnaires for adult siblings. These measures were designed to aid family intervention, though are used for retrospective purposes only. First there is a *Sibling Areas of Conflict* questionnaire which consists of 19 clusters of qualitative questions designed to give siblings more insight into their feelings about their situation and to

help clinicians to identify issues which are most problematic for adult siblings. Next is the *Parentified Child* questionnaire designed for individual use with adult siblings and parents or for use in an adult siblings group. There are 15 qualitative questions for adult siblings, such as "How strongly do you identify with the prototype of the parentified child?" along with five sentence completion activities. In addition, the questionnaire included four qualitative questions for parents, for example "Take a close look at your family. Is there one child who tends to take more care of the disabled child?" which aim to help parents reflect on their child's experience. Siegal and Silverstein included a *Withdrawn Child, Acting - Out Child* and a *Superachieving Child* questionnaire in their book with similar formats and a *Social Support and Family Resources Questionnaire* for use with adult siblings or parents to help them to better understand their own family and social supports. The authors explain that these questionnaires are designed as therapeutic exercises. As the questionnaires were not designed to be used as research tools, Siegel and Silverstein did not report exact methods used to develop any of these measures, nor did they report the psychometric properties of the various questionnaires.

Thomas Fish (1994) developed and distributes the *Sibling Need and Involvement Profile (SNIP)* through the 'Siblings Count Project' of the Nisonger Centre in Columbus. This measure has been 'field tested' with 24 families and intended to help families of children with special needs identify the strengths and challenges for their other children over the age of 4 years.

A series of statements are presented over five sections: *awareness, feelings, having fun, helping* and *advocacy* and are rated on 5-point Likert scale by parents. The front page of the measure suggests that the profile was designed to motivate discussion about sibling needs between parents and service providers and aid the development of support plans. As such, the measure has not been used for research in the area.

Furthermore, there are a number of versions of a sibling relationship/interaction scale reported in the literature. The researchers Wilson, McGillvray and Zetlin (1992) used the original version of the *Schaffer Sibling Behaviour Inventory* developed by Schaeffer and Edgerton (1979, as cited by Wilson et al., 1992). The measure originally consisted of 115 items covering 23 domains rated on a four-point scale ("Very Much Like" to "Not at all Like"). In Wilson et al.'s (1992) study siblings themselves rated each item. However, the researchers do not report any psychometric properties for the inventory.

The *Schaffer Sibling Behaviour Rating Scale* developed by Schaeffer and Edgerton (1979, cited by McHale et al., 1986) has also been adapted and published by McHale et al. (1986). This version of the measure has 24 items across four subscales validated through factor analysis: acceptance-rejection, warmth-hostility, contact-leadership and embarrassment (Roeyers & Mycke, 1995). Items are rated on a 5-point scale. The measure was

typically rated by parents though the measure has been used as a self-report inventory with children (e.g., Roeyers & Mycke).

Furthermore, McHale and Gamble (1989) reported using two of the subscales (warmth/hostility, contact/leadership) from the 1981 version of the Schaeffer and Edgerton Sibling Inventory Behavior (SIB). The researchers only used these two subscales from this measure due to less than ideal alpha levels of the other two subscales. Similarly, Bagenholm & Gillberg (1991) published the *Sibling Relationship Interview*, which they claim is adapted from the version reported in McHale et al. (1986) as well as Grossman (1972). The review published by these authors is a semi-structured 26-item interview schedule that covers four domains: Attitudes towards sibling relationship, sibling's family role, sibling/peer relationship and perceptions of self. These measures are primarily used to assess the relationship between siblings with and without special needs. The items are answered verbatim and then rated by the interviewer on a 6-point scale ranging from least to most adaptive response. Bagenholm and Gillberg report that one-third of the first scale was subject to an inter-rater reliability check with average Pearson product moment correlations being 0.96, however no other part of the interview schedule was checked. Furthermore, the researchers do not report any other psychometric properties for the interview schedule.

The literature reviewed above indicates that there have been very few measures developed to specifically assess the effect of disability on siblings.

Furthermore, the measures have not been developed using rigorous methodologies nor have extensive psychometric properties been reported for existing measures. If research on the needs of siblings is to move forward, a reliable and valid measure of the effect of disability on siblings is required. Research into the effects of disability on families and, more specifically, siblings will now be reviewed.

### **2.3 Effects of Disability on Families**

The effect of disability on families has been researched since the 1950s, with most focusing on the differences found between families who have a child with an intellectual disability (or special needs in general) and mainstream society. However an “explosion” of research in this area occurred in the 1970s and 1980s (Minnes, 1998). Some have argued that the effect on these families is great (such as Trevino, 1979), whilst others have noticed but a few unique differences between families who have a child with a disability and “mainstream” families. Table 2.1 lists some of the effects of disability on family life reported by past literature. Below is a brief coverage of the literature, with section 2.4 providing a more complete coverage of research specific to siblings.

Research conducted by Kirkman (1985) on a sample of 151 Australian adult siblings found a high percentage (59%) believed that the impact of a child with a disability had an overall negative impact on their family as a whole. The main negative effects were found to be “stress; restricted activities;

family life revolving around the child with the handicap; disrupted parental relationship; distortions of subsystem configuration; and overt pathology" (Kirkman, p. 4). Furthermore, 39% of adult siblings in the study reported that having a brother or sister with a disability had a negative effect on their relationship with their mother and 33% reported a negative impact on their relationship with their father.

Table 2.1

*Effect of Disability on Family Life*


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|                                              |                              |
|----------------------------------------------|------------------------------|
| Stigmatisation                               | McKeever (1983)              |
| Increased attention on child with disability | Bronfenbrenner (1979)        |
| Increased responsibility for siblings        | Sheres (1956)                |
| Decreased marital satisfaction               | Friedrich & Friedrich (1981) |
| Increased stress on family                   | Senel & Akkök (1996)         |
| Decreased psychological well being           | Friedrich & Friedrich (1981) |
| Decreased social support                     | Friedrich & Friedrich (1981) |
| Parentification of siblings                  | Lamorey (1999)               |
| Isolation                                    | Roe (1986)                   |
| Role tension                                 | Farber (1959)                |
| Impaired family recreation and socialisation | Kirkman (1985), Nesa (1999)  |

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A consistent finding in the literature was that many families felt their home life was different from other families. For example, Nesa (1999) found that 63.3% of siblings believed that life in their family was "quite a bit different" from life in other families because of their brother or sister with Down syndrome. Similarly, most researchers agree that these families experience

more stress than other families in the community (e.g., Pless & Pinkerton, 1975). Walton (1993) explains that families who have a child with a disability have “unique stressful circumstances, which can bring excessive stress into their lives”, (p. 116). Senel and Akkök (1996) found that the stress levels of a group of 30 siblings of children with disabilities (ranging from 13 to 20 years of age) were significantly higher than those of 30 siblings of children with no disabilities. Furthermore, these researchers found no significant effect of the gender, family size and educational level of each group on the stress levels of both groups. Despite the study having a small sample which was limited by an overrepresentation of older siblings (26 out of the 30 participants were older than their sibling with a disability) and females (22 participants were female), the difference in stress levels between the two groups were still significant.

The amount of time and attention required in caring for the child with a disability is one of the most frequently reported influences on families. Bronfenbrenner (1979) observed that an indirect effect on the family is the possibility of all of the parents' energy being focused on the child with special needs. Vigilante (1983) suggested that the extra care demands placed on families might affect their overall functioning through mealtimes, vacations, house space and recreational time. Early research by Shere (1956) found that parents of twins (one with cerebral palsy and the other nondisabled) displayed more awareness of the disabled twin's problems than the problems of their nondisabled child. Furthermore, Rayner and Moore (2004) reported

on the preliminary findings of a research study involving 55 siblings of children with chronic illness/ disability between the ages of 7 and 18 years. The researcher found that parents' reporting of siblings' attention seeking were generally higher than the norm. Many believe that a typical issue for families of children with special needs is that with the main direction of attention being on the child with special needs, the attention needs of the siblings are often overlooked (e.g., Vigilante; Weaver, 1999; Widdows, 1997).

Along with decreased attention, care-taking responsibilities have been an important topic in research exploring the sibling relationship in families with a child with a disability. Nesa (1999) found that almost half of the siblings in her study believed that they had to be more helpful because of their brother or sister with Down syndrome. Similarly, the results of Shere's (1956) study indicate that parents of twins (one with cerebral palsy and the other nondisabled) expected the nondisabled twin to take on the majority of responsibilities. A number of studies report that it is the older siblings, especially older sisters, who are often expected to take on the majority of caretaking responsibilities (e.g., Brody, Stoneman, Davis, & Crapps, 1991; Cleveland & Miller, 1977). However, Stoneman, Brody, Davis, Crapps and Malone (1991) found that in some cases younger siblings of children with an intellectual disability may take on childcare responsibilities evident in the oldest sibling in typical families. These researchers found that the higher the childcare demands of younger siblings, the lower the number of conflicted interactions between the child with an intellectual disability and their sibling.

It has also been argued by Farber (1959) that the lesser the competency of the sibling with an intellectual disability, the greater the burden on the family, increasing the likelihood of siblings helping out.

Another effect that has emerged from the literature is that of "role tension". Farber (1959) investigated the idea of "role tension" – a situation where a younger sibling moves into the "older child" role within the family as they developmentally overtake their brother or sister with an intellectual disability. This situation can be confusing for all individuals concerned and "heightens tension in interactions and, in doing so, inhibits the child's adjustment to his [*sic*] roles" (Farber, p. 50). Farber gathered evidence to suggest that siblings who interacted frequently with their brother or sister with an intellectual disability were more likely to experience role tension than siblings who interacted less frequently with their brother or sister. Furthermore, Farber argued that in cases where mothers classified the child with a severe intellectual disability as *highly dependent*, role tension was greater in siblings.

Positive effects for families have received less focus in the literature, however some argue that there are many benefits for families (e.g., Blacher & Hatton, 2001). Trachtenberg and Batshaw (1997) review some of the effects that have been reported in past literature. These include parents finding caring for the child with a disability as rewarding. Trachtenberg and Batshaw suggest that caring for a child with a disability may help mothers to feel competent and gain a sense of accomplishment while fathers may feel

“pleasure from an enhanced role in daily family life” (p. 747). Stainton and Besser (1998) identified nine themes surrounding the positive impact of disability on families. These included increased spirituality, and an enhanced sense of purpose and priority, and families obtaining a sense of unity and cohesion. Similarly, McAndrew (1976) found many parents in her study believed that having a young child with spina bifida, cerebral palsy or limb deficiency had strengthened their marriage. However, as McAndrew acknowledges, as well as others (e.g., Siegel & Silverstein, 1994), there are many factors that influence the parents’ relationship, such as their functioning before the birth of the child with a disability, which need to be taken into account. Many parents in Riper’s (1999) study reported that positive consequences of rearing a child with Down syndrome outweighed the negative consequences. Increased family cohesion, a broader perspective on life, diversity and finding the genuine meaning of unconditional love, were listed as positive consequences that families had experienced. Similarly, qualitative comments reported by Mittler (1995) indicate that many families can identify the practical benefits gained from having a child with a disability, such as the contribution the child with a disability has made to family life, an enhanced understanding of disability and the meaning of one’s life, an enhanced appreciation for their own strengths and a sense of pride.

In summary, the research literature suggests that increased familial stress, attention mainly focused on the child with a disability, increased caretaking responsibilities for siblings, and the possibility of younger siblings

experiencing role tension may be some of the major influences of the presence of a child with a disability on the family. However, positive effects reported in the literature include a parents' feeling a sense of competence or purpose, the marital relationship may be strengthened and increased family cohesion.

## **2.4 Perceived Effect of Disability on Siblings**

### 2.4.1 Perceived Effect of Disability on Family Life

The effect of disability on siblings fall into two main areas: family life and social life. The effects discussed in Section 2.3 impact on the family as a whole and indirectly on siblings within the family. However, there have been influences found which are specific to the siblings in the family. These include positive effects, negative effects and a more balanced view.

#### *2.4.1.1 Positive Effects*

Studies have found positive affects in the area of increased understanding or helpfulness. For example, Jacobs (1969) found siblings to be generally sympathetic, understanding and helpful, illustrating that they were not unfavourably affected by having a disabled brother or sister. In addition, McHale et al. (1986) found that siblings tended to be supportive and accepting of their brother or sister with an intellectual disability and Miller (1974) found that some siblings exhibit a sense of pride in being able to aid the development and growth of their brother or sister with a disability.

An additional factor is increased feelings of responsibility. Wilson et al. (1989) found that younger siblings of children with severe disabilities demonstrated a consistently high level of participation in the day-to-day activities of their brother or sister with special needs. They also tended to emphasise the positive aspects of their family life, without 'glossing over' the difficulties of having a brother or sister with special needs.

#### *2.4.1.2 Negative Effects*

Whilst the positive effects of having a brother or sister with an intellectual disability highlighted in the literature, negative consequences have also been reported. These include siblings experiencing increased feelings of shame, anger, guilt (Grossman, 1972), loneliness (Bagenholm & Gillberg, 1991), anxiety (Rayner & Moore, 2004; Wasserman, 1983), behavioural problems (Tritt & Esses, 1988), aggression (Rayner & Moore, 2004), caretaking responsibilities (Farber, 1960), dominance (Begun, 1989), and overall poor adjustment, (McHale & Gamble, 1989). In addition, as discussed previously, researchers have reported the occurrence of role tension or crossover (Brody et al., 1991; Farber, 1959), deprivation of parental attention and stigmatisation (McKeever, 1983).

Clinical observations have provided further information. Observations by San Martino and Newman (1974) revealed that siblings of disabled children were an easily recognisable group. They reported that some younger siblings were observed to over-identify with their brother or sister with an intellectual

disability and thus found it difficult to establish their identity as separate from that of their sibling. Schild (1964) also (informally) observed that nondisabled children were finding it difficult to relate to the experience of having a brother or sister with an intellectual disability.

Woodburn (1973) and Gath (1973) found reactions of jealousy, resentment and embarrassment to be common for the non-disabled sibling. Interviews with ten siblings conducted by McConachie and Domb (1981), however, did not find apparent differences in levels of embarrassment, conflict, amount of domestic work, or the playful interaction between siblings of children with an intellectual disability and a comparison group. However, it is important to note that this latter study utilised a small sample giving little opportunity for any differences to emerge. Research by Carr (1995) suggested that jealousy reactions may decrease with age. Her results indicated that 48% of siblings of children with Down syndrome reported experiencing feelings of jealousy at age 4, whilst only 33% reported jealousy at age 11 and none at 21 years of age. The study also found that jealousy was more likely to occur when the age difference between the siblings was less than two years.

Concern about the future also appears to be an issue for some siblings.

Wilson et al. (1992) found that although the brothers and sisters in their study reported a stable positive attitude towards their sibling with a disability, most of the siblings in their sample tended to regard their brother or sister with a disability as a lifelong commitment. These results are similar to those

of Bagenholm and Gillberg (1991) who compared 20 children who had a brother or sister with autism, 20 children who had a brother or sister with an intellectual disability and 20 children who did not have a brother or sister with any disability. They found that the siblings of children with autism or an intellectual disability overall appeared more concerned about the future than the comparison group and often viewed their disabled brother or sister as a 'burden'.

#### 2.4.1.3 *A More Balanced View*

A number of studies have given us a fuller picture of what life is like for siblings by providing a more balanced view of both positive and negative effects (e.g., Grossman, 1972; Leonard, 1997; Nesa, 1999). Grossman reported that 45% of the young adult college students surveyed believed that they had suffered because they had a brother or sister with a disability. Nevertheless, an equal percentage of siblings reported *benefits*, which included increased compassion, tolerance and understanding for others. Similarly Leonard asked parents to outline the positive *and* negative facets of siblings' experience of having a brother or sister with Down syndrome. Over two thirds of siblings reported negative effects such as time restrictions and increased parental stress; impaired family recreation and socialisation; embarrassment by sibling and ostracism by peers; no regular sibling relationship and increased responsibilities. However, over 70% reported positive facets of their experience such as tolerance and understanding of disability and differences; patience and willingness to help; compassion and

care; appreciation of one's own talents and life in general; and greater maturity and strength. Nesa (1999) found similar results in interviews with 7-13 year old siblings with all of the participants in the study reporting that they enjoyed having their brother/sister with Down syndrome in their family. However, they did display concern over the future and the reactions of their peers. In accordance with this, the work of Furman and Buhrmester (1985) documented over 65% of siblings in their study as reporting positive aspects in their relationship with their siblings such as admiration, affection and companionship, while 91% reported antagonism as a negative aspect of their relationship and 79% stated that quarrelling occurred often.

The literature reviewed suggests that it is likely that there are both positives and negatives influences on the family lives of siblings of children with a disability. A number of studies (e.g., Crnic & Leconte, 1986) have suggested that peer-related areas of siblings' lives are influenced. Hence, another important area of impact is a sibling's social life.

#### 2.4.2 Perceived Effect of Disability on Social Life

Research conducted on the effects of having a sibling with an intellectual disability has been extended to social life. Table 2.2 (below) outlines the main findings of research reported in this area.

Table 2.2

*Effect of Disability on Social Life*


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|                                                                   |                                           |
|-------------------------------------------------------------------|-------------------------------------------|
| Discomfort or difficulty in explaining sibling                    | Nesa (1999);<br>Powell & Gallagher (1993) |
| Less opportunity to engage in out-of-home activities              | Crnic & Leconte (1986)                    |
| Teasing<br>(1995)                                                 | Atkinson & Crawforth                      |
| Peers afraid or uneasy around sibling with disability             | Trevino (1979)                            |
| Parents want healthy sibling to include sibling with a disability | Trevino (1979)                            |
| Child assumes "Brother's Keeper" role at school                   | Powell & Gallagher (1993)                 |

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The issue of whether or not the child with a disability attends the same school as the other siblings is likely to have various consequences for the social life of the other siblings at school. Powell and Gallagher (1993) argue that at some stage in their life, children with a disability typically attend the same school as their siblings. These authors suggest that this group's unique situation of being a "brother's keeper" at school may "keep a sibling from informal, yet important social interactions with friends," (p. 182-183).

Some siblings appear to have trouble explaining to their peers about their brother or sister with an intellectual disability and thus feel some discomfort. Nesa (1999) found that 57% of the siblings in her study had difficulty explaining their sibling with Down syndrome to their friends. Nevertheless,

only a small percentage (13%) of participants indicated that they would rather people didn't know that they had a brother or sister with Down syndrome. Along these lines, Powell and Gallagher (1993) suggested that "some siblings may claim that the child is either adopted or a cousin", (p. 183). Seventy percent of siblings in Atkinson and Crawford's (1995) survey reported being bullied or teased at school as a result of their brother or sister's disability.

Wilson et al. (1992) interviewed 30 adult siblings about their attitude towards their sibling with an intellectual disability and their ratings of behavioural competency. Analyses of the interview data revealed that discomfort in relation to their sibling generally decreased with age with many siblings reporting a lack of concern about how others react to their brother or sister with a disability in adulthood. Despite this overall result, the teenage years were identified as the time when siblings reported being most concerned about peer rejection, reporting great embarrassment and discomfort. The researchers do note that retrospective responses were confounded by participants' memory and the prospective responses may have been influenced by social desirability. Nevertheless, adolescence is a time when peer acceptance is particularly important for all children (Keydel, 1988).

Next, it has been argued that siblings have fewer opportunities to engage in out-of-home activities (e.g., Crnic & Leconte, 1986). An obvious factor is that extra care giving responsibilities may result in less contact with friends. It is

evident that the extra care demands placed on the sibling may impact on the amount of time available for them to visit friends and engage in other out-of-home activities that other children their age are engaging in (Crnic & Leconte). Some argue against this, for example, Stoneman et al.'s (1991) results suggest that siblings' socialisation was unrelated to their childcare or household responsibilities.

Other researchers have found evidence that suggests that discomfort on behalf of other children may result in siblings having less contact with friends (e.g., Trevino, 1979). This may occur because peers have little understanding about disabilities. Younger children may also be afraid or feel uneasy around the child with a disability and consequently may decide that they do not want to visit their friend who has a brother or sister with a disability (Trevino). An additional stress for siblings that Trevino found was that parents often wanted them to include their sibling with a disability in activities with peers.

The effects of having a sibling with an intellectual disability extends to social life, with some children having difficulty explaining to their peers about their sibling, children feeling some discomfort interacting with the child with a disability, or other factors such as extra demands placed on the siblings resulting in less time for out-of-home contact with friends.

## 2.5 Predictors of Adjustment<sup>1</sup> for Siblings

Many researchers in this area have focused on how siblings of children with special needs differ from other children in the population, with many focusing on their "adjustment". Some argue that siblings may be at risk of adjustment problems (e.g., Bagenholm & Gillberg, 1991; Breslau & Prabucki, 1987; Colby, 1995; Lobato, Barbour, Hall, & Miller, 1987). Others argue that there is no difference between the psychological adjustment of siblings of children with special needs and siblings in mainstream society (e.g., Auletta & DeRosa, 1991; Bischoff & Tingstrom, 1991; Gath & Gumley, 1987; Hannah & Midlarsky, 1999).

Research that has explored the adjustment of siblings of children with special needs compared to other siblings of children with no disabilities has raised various methodological issues. Cuskelly, Chant and Hayes (1998) argued that comparison groups used for past studies have often been insufficient. They contend that some studies have simply compared sibling data with normative data while others have failed to specify the equivalence of participants in experimental and comparison groups on important demographic variables. Similarly, most studies have lacked control groups and thus wrongly assumed higher numbers of psychological problems in siblings. Ferrari (1984) reported that studies that included control groups have generally reported lower levels of psychological adjustment problems.

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<sup>1</sup>\*This term has been chosen to represent the range of labels researchers have used in their research such as "behavioural adjustment" and "adaptation", that are believed essentially to measure the "effect of disability".

Summers, White and Summers (1994) conducted a review and analysis of literature in the area and found “the higher the quality of the study, the less likely a significant effect was to be found”, (p. 180). Nevertheless, there are a number of variables that have been found to influence the adjustment of siblings in the family.

### 2.5.1 Demographic Factors

Demographic factors are associated with adjustment and behaviour problems in children in general and hence have been found to be associated with adjustment of siblings of children with disabilities. Table 2.3 outlines some of these variables.

Table 2.3

#### *Demographic Factors Influencing Sibling Adjustment*

| Demographic Factors          | Researchers                                                               |
|------------------------------|---------------------------------------------------------------------------|
| Gender                       | Crnic & Leconte (1986); Farber (1959); Grossman (1972);                   |
| Age                          | Stoneman & Brody (1993)                                                   |
| Birth-order                  | Lobato (1990); Stoneman & Brody (1993); Graliker, Fishler, & Koch, (1962) |
| Age-gap between siblings     | Lobato (1990); Stoneman & Brody (1993); Wilson et al. (1989)              |
| Number of children in family | Lobato (1990)                                                             |
| Socio-economic status        | Crnic & Leconte (1986); Grossman (1972)                                   |
| Extent of disability         | Henderson & Vandenberg (1992); Minnes (1988); Stoneman & Brody (1993)     |
| Type of disability           | Hodapp, Fidler, & Smith (1998)                                            |

Birth order appears to mediate sibling functioning with first-born children and older siblings being less affected than younger siblings (e.g., Galiker et al., 1962; Grossman, 1972). One explanation for this is that first born and older children have had a period of time where they have been in a 'typical' family household and thus less likely to be influenced when the child with a disability is born.

Lobato (1990) and Stoneman and Brody (1993) argue that the age-gap between siblings impacts on their adjustment. For example, Wilson et al. (1989) report that siblings in their study who were less than three years apart got along extremely well, and suggest that the closer in age the greater the similarity between the two. Others have not found evidence to support the relationship between these two variables (e.g., Abramovitch, Corter, & Lando, 1979; Abramovitch, Corter, & Pepler, 1980; Dunn & Kendrick, 1982).

The extent of a child's disability also appears to impact on siblings. Minnes (1988) reported that parents of children with a mild disability may experience less stress than those of children with a severe disability, however Minnes explains that the contrary has also been found. Many individuals with an intellectual disability also have other disabilities that may influence a sibling's home life. The Australian Institute of Health and Welfare's (AIHW, 2003) report on "Disability Prevalence and Trends" reported that many individuals with a disability have more than one type of impairment or condition. The *type* of disability has also been found to influence siblings' adjustment. For

example, Hodapp et al. (1998) compared the stress levels of families with Smith-Magenis syndrome in their study, with those of studies published with families of children with other disabilities. The authors argue that families of children with Smith-Magenis, Prader-Willi and Cri Du Chat syndrome may experience higher levels of family stress than those with unknown or mixed aetiologies, though the reason for this is unclear. However, Hodapp et al. found that levels of social support along with impairments in childrens' socialisation skills influenced parent-family problems and thus stress levels of families of children with Smith-Magenis syndrome.

### 2.5.2 Other Psychosocial Factors

Other variables that have been investigated in relation to sibling adjustment include psychosocial factors for the individual child or the family. These variables are presented in Table 2.4.

Table 2.4

#### *Other Variables Influencing Sibling Adjustment*

| Other Variables              | Researchers                           |
|------------------------------|---------------------------------------|
| Temperament                  | Dunn & Kendrick (1982)                |
| Parental attitudes           | Cadwell & Guze (1960); Trevino (1979) |
| Family support and resources | Dyson, Edgar, & Crnic (1989)          |
| Parental stress levels       | Dyson et al. (1989)                   |
| Knowledge of disability      | Roeyers & Mycke (1995)                |

Temperament has been linked to sibling adjustment with Dunn and Kendrick (1982) finding evidence that siblings' temperament before the birth of their brother or sister with special needs were strongly correlated with parental reports of problems later on. In addition, the knowledge of their sibling's condition appears to influence adjustment. For example, Roeyers and Mycke (1995) found siblings' knowledge of their brother or sister's autism was related to the quality of the sibling relationship, with increased knowledge of aetiology correlated with a more positive sibling relationship (as measured by acceptance-rejection, warmth-hostility, contact-leadership and embarrassment).

Family factors appear to impact directly on sibling adjustment. For example, Schreiber and Feeley (1965) argued that parental attitudes that are "constructive" and "supportive" allow siblings to gain a greater sense of responsibility, develop greater maturity, patience and tolerance. Grossman (1972) stated that mothers' attitudes in particular are very influential on children's acceptance of their sibling with a disability, while Peck and Stephens (1960) suggested that a father's attitudes might affect the adjustment of the whole family. In addition, Dyson et al. (1989) found that family attention to personal growth was an important factor in sibling adjustment.

Trevino (1979, p. 489) argues that the following combination of factors produce adverse affects on sibling's adjustment:

- 1) There are only two siblings, a normal and a handicapped child,
- 2) The normal sibling is close in age to or younger than the handicapped sibling, or is the oldest female child,
- 3) The normal and handicapped child are the same sex, or
- 4) The parents are unable to accept the handicap.

Trevino (1979) contends that "normalcy" in families of children with a disability increases with the number of non-disabled siblings, with the available help for caregiving potentially increasing with the number of non-disabled siblings. Role tension may also occur when siblings are close in age to their sibling with a disability, or are younger than the child with a disability (Trevino). Trevino states that many researchers have found that it is the eldest female child who carries the most burden of responsibility for the child with a disability. Younger children who are the same sex as their brother or sister with a disability may have difficulty developing a separate identity, particularly if there are no other non-disabled siblings in the family (Trevino). Last, Trevino argues that parents who have difficulty accepting the child's disability may project their feelings onto the other children in the family, be less available for them or have different ways of interacting with the child with a disability and other family members. The combination of the above factors may result in a particularly challenging prospect for siblings.

### 2.5.3 Developmental Stages and Disability

Many researchers argue that the age of the sibling without a disability as well as their age in relation to the child with a disability are important factors in their adjustment. For example, many have found that first-born children and older siblings are less affected by having a brother or sister with a developmental disability than younger siblings (e.g., Galiker et al., 1962; Grossman, 1972). Lobato (1993) found that preschool aged siblings were more vulnerable than older siblings to behavioural adjustment problems. Breslau (1982) further found that young male siblings appeared to be the most at risk of adjustment problems.

A sibling's developmental stage appears to be an important factor when considering the effects of having a sibling with an intellectual disability (Skrtic, Summers, Brotherson, & Turnbull, 1984). However, of the research that has been conducted on sibling needs, most has focused on younger siblings, i.e. under the age of 12 years, with the effects on teenagers being relatively unknown. Thus, of concern for the present study is the unique developmental stage of adolescence.

Adolescence is a time when individuals are trying to understand themselves as distinct from others. Keydel (1988) argues "Having a disabled sibling is a difference that sets adolescents apart from peers and makes the task of establishing an identity that is separate from the family much more difficult," (p. 204). Havighurst (1974) argued that the changes that occur during

adolescence can be represented in terms of tasks. Of the eight tasks listed by Havighurst (pp. 43-82), the following seven tasks appear to be of particular importance for siblings of children with an intellectual disability:

- Achieving new and more mature relations with age mates of both sexes
- Desiring and achieving socially responsible behaviour
- Acquiring a set of values and an ethical system as a guide to behaviour
- Achieving a masculine or feminine social role
- Achieving emotional independence of parents and other adults
- Preparing for an economic career
- Preparing for marriage and family life

The situation of families who have a child with an intellectual disability impacts on the above tasks in various ways. For example, preparing for marriage and family life may include the realisation that one may have to care for his/her sibling with a disability when the parents are no longer able to. In addition to this, they may take into account acceptance of the sibling with a disability on behalf of their marriage partner. Skrtic et al. (1984) argue "adolescents are frequently asked to share responsibility for care of the handicapped sibling, and may also be pressured to achieve in school or in sports to compensate for the lack of achievement by the handicapped child" (p. 239).

Consequently, adolescence may be an easy or a relatively difficult stage, depending on the stressors present. The present research aims to concentrate on older teenage siblings, as this is a relatively unexplored area of research.

## **2.6 Problems of Past Studies**

Despite the extensive research focusing on the family adjustment of having a child with a disability, most research has focused on the parents of the child or the family unit (e.g., Byrne & Cunningham, 1985; Failla & Jones, 1991; Frey, Greenberg, & Fewell, 1989; Heaman, 1995; Lambrenos, Weindling, Calam, & Cox, 1996; Leyser & Dekel, 1991; Sloper, Knussen, Turner, & Cunningham, 1991) with fewer mentioning the specific needs of siblings. The sibling relationship has been regarded as one of the most important relationships people experience throughout their lives (e.g., Irish, 1964; Lobato, 1990) and thus the impact of having a sibling with an intellectual disability should be considered when trying to interpret their behaviour.

Sibling ages have also varied greatly with most studies including siblings from very large age ranges and both younger and older siblings (Cuskelly, 1999).

This makes it difficult to compare the results of different studies and may have an effect on the outcomes, as studies have shown that a child's age influences his or her adjustment (e.g., Lobato, 1993) as well as their age in relation to the child with a disability (e.g., Grossman, 1972).

Other characteristics such as affiliation with an agency also appear to have influenced past research results. Trevino (1979) argued that as most of the participants in studies have been affiliated with an available mental health service, samples in many studies have been biased. This is often unavoidable as it is typically through these agencies that participants are recruited.

Of major concern to most studies in this area is participant numbers. While many disability organisations have information on the child who has a disability and their parents, they typically hold no information on whether or not the child has siblings and if so what their age or gender is (Nesa, 1999). This makes it challenging for researchers to recruit sufficient participants to meet statistical power requirements. Researchers have to work hard to recruit potential participants for their research without biasing their population.

There are a number of problems found in past research, including recruitment methods, limited samples and lack of control groups, some of which are difficult to avoid. The present study aims to rectify some of the problems that have been found in past research, in order to produce not only reliable and valid results, but a current account of the feelings of siblings.

## **2.7 Overall Conclusions of Past Studies**

There is significant evidence to suggest that disability not only impacts on the individual, but family members and carers as well. The literature indicates

that family members may experience higher levels of stress than the child with an intellectual disability. However, many of these studies overlook the specific effect on siblings despite the fact that the impact on siblings typically occurs throughout their life span with many left as the primary carers for their brother or sister with an intellectual disability when their parents are unable to be carers or when they pass away.

The literature review has revealed the following effects on sibling's family lives: stigmatisation, decreased social support, less attention from parents and increased responsibility. Moreover, research has shown many influences in the social lives of siblings including: less opportunity to engage in out of home activities, teasing, ostracism by peers and difficulty explaining to peers about their sibling with a disability.

Some of the research has focused on the adjustment of this group compared to comparison groups. However, it is difficult to draw meaningful conclusions from some studies due to methodological problems with measures, sample sizes and generalisation. There are numerous factors that influence the adjustment of siblings. Demographic factors such as age, gender, family size and birth order have been shown to be related. However, it is important to note that some of these variables are correlated with adjustment for children in general. Other variables discussed that may impact on adjustment levels of siblings specifically include parental stress levels, social support, type of disability, and severity of disability.

### 2.7.1 Past Measures and Rationale for the Development of a New Measure

There have been very few measures that have been developed to specifically assess the effect of disability on siblings and none that have been developed from a rigorous methodology. Of the measures that exist, the methodology used to develop them has been unclear, siblings do not appear to have been consulted and the psychometric properties have not been reported. Thus it is believed that a reliable and valid measure of the perceived effect of disability on siblings is required if research is to move forward in this area.

Some studies have relied on parental reports, rather than sibling accounts of their experiences. It can be argued that parental views may give a different picture of what is truly happening, and the point of view of the sibling may be neglected through this method. Wasserman (1983) explains that parental reports “may be somewhat distorted by the parents’ own frustrations and needs” (p. 622). Furthermore, Cuskelly, Chant and Hayes (1998) argue that parents might be influenced by their own levels of stress when completing behavioural reports.

Rowitz (1993) maintains that many researchers rely on standardised measures that may not be appropriate for the research issue. He suggests that the development of instruments specific to the area is vital if future research is to be reliable and valid. Hence, the development of a reliable and valid measure for use with older teenage siblings is needed in order to meet

their unique needs, to assist the development of interventions and to assess sibling resilience.

## **2.8 Aim of Study 1**

Study 1 involves the development of a self-report measure of Perceived Effect of Disability for teenage siblings of children with an intellectual disability. The measure was developed to accurately represent the effect of having a brother or sister with an intellectual disability on the family and social lives of teenage siblings. A multi-method approach was used in the development of the measure, which occurred across three stages, combining both qualitative, and quantitative data in order to produce the most reliable and valid measure possible.

## *Chapter 3: Study 1: Measure Development Stage 1*

### **3.1 Aim**

Stage 1 of this study involved the development of an item pool forming the Perceived Effect of Disability measure. In this chapter the materials and procedures relating to the development of the measure are discussed along with the recruitment of the sample. This is followed by the results of the item pool selection and reduction process and discussion of this first version of the instrument.

### **3.2 The Multi-Method Approach**

Substantive theorising emphasises the importance of researchers having a number of paths to follow, using multiple methods and becoming very familiar with the domain in which they are researching (Wicker, 1989). One path researchers can follow is to initially focus on conceptual concerns, then explore the substantive domain and finally consider the methodology to be employed (Wicker). This path was taken in the present study, with conceptual concerns first addressed, then the substantive domain explored in order to develop a comprehensive initial item pool for the perceived effect of disability on teenage siblings. Wicker (p. 539) argues, "Substantive theorising...does require multiple methods to expose more of the domain than can be learned from a single approach". In the present study multiple

methods were used to develop an item pool and investigate the validity of the items as well as to reduce the item pool.

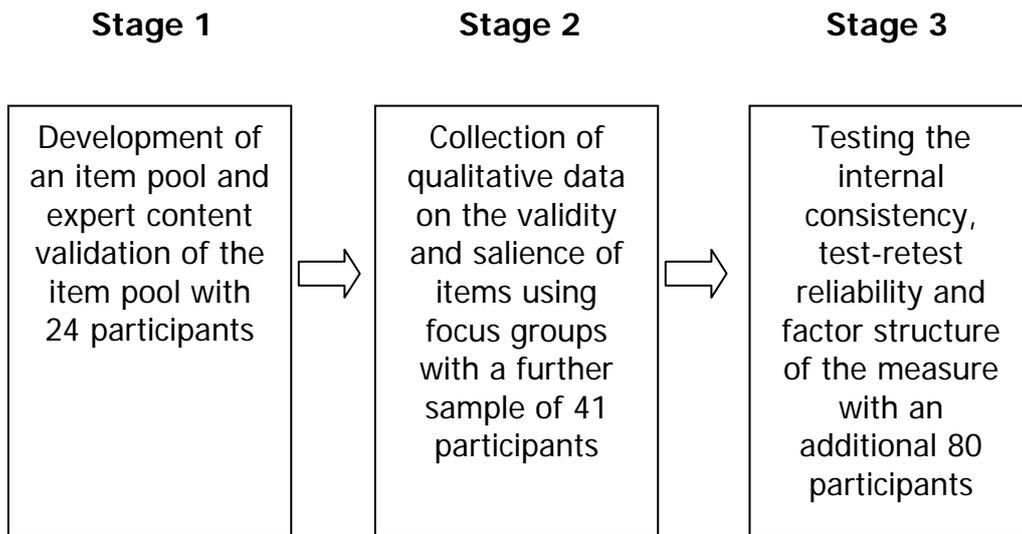
First, the methodology of Study 1 followed some of the principals of 'theoretical keying'. Shackelton and Fletcher (1984) explain the process of theoretical keying as initially "writing a large number of items that seem likely to tap [the construct measured]...they may be chosen on theory or intuition" (Shackleton & Fletcher, p. 89). Thus multiple sources of information were used to develop a large initial item pool. In total 149 sources of information including journal articles, existing measures and books (see Chapter 3) were examined for potential items. In the present study, siblings themselves served as the "experts" who evaluated the importance/relevance of items and issues presented through questionnaires completed in their homes. Collection of qualitative data on the validity and salience of items was then conducted through the use of focus groups.

Focus groups are a valuable source of data collection that can be used as the primary method for collection of data, as an additional method or in multi-method studies such as the present study (Morgan, 1997). Focus groups have the advantage of participants being able to expand on issues or themes presented and also to react on those presented by others (Dalton, Elias, & Wandersman, 2001). The focus groups conducted in the present study then provided data that ensured that the item pool was valid and reliable and this data were then combined with that of the first stage to further refine the item

pool. Including focus groups in the present study ensured that the measure covered issues that were indeed important for the population addressed, and provided further exploration of items selected in Stage 1.

Testing the internal consistency, test-retest reliability and factor structure of the measure was the last step. Following theoretical keying principals described by Shackleton and Fletcher (1994) an important procedure in measurement development is "...those items that do not seem to be grouped with others would be deleted, on the ground that if items are measuring the same thing they should be associated (correlated) with one another" (p. 89). Hence, Stage 3 involved the removal of items that did not add to the overall reliability of its respective subscale or load highly on the measure's factors.

Thus, the Perceived Effect of Disability measure was developed in three stages that combined a collection of both qualitative and quantitative information from teenage siblings. No measure to date has used siblings as experts in the development of a measure specific to this population. These three stages are summarised in Figure 3.1:



*Figure 3.1* The three stages comprising Study 1.

This multi-method approach ensured that the final Perceived Effect of Disability measure adequately represented the views of teenage siblings of children with an intellectual disability in Western Australia.

### **3.3 Measure Development**

#### **3.3.1 Item Selection Pool**

A thorough search on PsycINFO 2001 was conducted using the following descriptors: disability, siblings, and adjustment. One hundred and thirty-nine sources of information were found and used to construct the items and sort them into subscales. These sources included 3 measures (two published and one unpublished), 77 journal articles, 8 newsletter/magazine articles, 23

books, 26 chapters from edited books and 2 workshop manuals. See Appendix A for a full list of the sources used.

Potential items were constructed from the sources by extracting a number of direct quotes, common themes and scenarios for siblings, stories or research findings from the sources. This procedure ensured that the item pool had good content validity. In addition, 21 existing items from the three measures (The Sibling Impact Questionnaire referred to in Eisenberg et al., 1998; The Sibling Problem Questionnaire by McHale et al., 1986; and The Sibling Statement Scale by Wilson et al., 1989) were used. These items were kept identical or only reworded slightly to ensure the content of the item was retained. The items that originated from these measures are listed in Table 3.1. In total, 150 potential items were constructed in this process. An expert panel of researchers and clinicians then reviewed the item pool. These researchers provided feedback on the selection of items that was then incorporated into the pool and final measure. Validation of these items then involved sending teenage siblings of children with an intellectual disability a draft of the item pool and asking them to indicate the importance/relevance of items and subscales for them, as described below.

### 3.3.2 Item Pool Reduction

Thematic analysis was used to sort items into themes and subthemes. The themes emerging from the literature fell into two main groups - those affecting siblings' family life and those affecting siblings' social life. These

formed Part 1 and 2 of the measure respectively. Therefore, the 150 potential items were sorted into these main areas. Items were then further sorted into subthemes. Twenty-six subthemes were identified and formed the subscales of the measure. Thus, there were 26 subscales in total, with 14 of these related to siblings' family life and 12 subscales relating to siblings' social life. Version 1 of the measure comprised 150 items with 26 subscales, as presented in Table 3.2.

### 3.3.3 Expert Content Validation

After the item pool for version 1 of the measure was developed and items were sorted into their respective parts and subscales, a content validation process was implemented. Version 1 was given to participants in order to determine which items should be included in the final version, and which items need further exploration. Siblings of children with intellectual disabilities were considered experts in this area and hence they constructed the expert content validation sample. Recruitment of siblings for this validation is described below.

Table 3.1

*Items Originating from Existing Measures*

| Measure                                                                                               | Item                                                                                                    |
|-------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|
| Sibling Impact Questionnaire<br>(Referred to in Eisenberg et al., 1998)                               | "I think having a brother or sister with an intellectual disability makes my parents expect more of me" |
|                                                                                                       | "Other people may think that there is something wrong with me because ..... has a disability"           |
|                                                                                                       | "I wish I didn't have to take care of ..... so much of the time"                                        |
|                                                                                                       | "Because of ..... 's needs, it's hard for me to think about moving out and starting my own life"        |
|                                                                                                       | "I think having ..... in our family has made me a more patient person"                                  |
|                                                                                                       | "I appreciate my own health more because of ..... 's disability"                                        |
|                                                                                                       | "I think having ..... in our family has helped me understand more about other people's feelings"        |
| The Sibling Problem Questionnaire<br>(McHale et al., 1986)                                            | "Having ..... in our family has helped me to learn how to cope with stress and worry"                   |
|                                                                                                       | "I like having ..... in our family"                                                                     |
|                                                                                                       | "My parents don't mind if their children aren't perfect"                                                |
|                                                                                                       | "Sometimes I think of ..... as lucky because s/he gets special treatment"                               |
|                                                                                                       | "I'd rather people didn't know I had a brother/sister with a developmental disability"                  |
|                                                                                                       | "People feel too uncomfortable to talk about ..... with me"                                             |
| The Sibling Statement Scale<br>(Wilson et al., 1989)                                                  | "At times I don't like the way ..... interferes with my plans"                                          |
|                                                                                                       | "Living with ... has taught me a lot about people that are different"                                   |
|                                                                                                       | "If I didn't help out my mum would have too much work taking care of ....."                             |
|                                                                                                       | "If I didn't help out my dad would have too much work taking care of ....."                             |
|                                                                                                       | "I think having a brother or sister with an intellectual disability makes my parents expect more of me" |
|                                                                                                       | "My mum has to spend so much time taking care of my brother that she doesn't have enough time for me"   |
| "My dad has to spend so much time taking care of my brother that she doesn't have enough time for me" |                                                                                                         |
|                                                                                                       | "I wish I didn't have to take care of.... so much of the time"                                          |

Table 3.2

*Subscales Forming Part 1 and 2 of the Measure*

| Part                                                   | Subscale                                                                    | No. of Items                                   |
|--------------------------------------------------------|-----------------------------------------------------------------------------|------------------------------------------------|
| Part 1: Family Life                                    | Learning from their brother or sister's disability                          | 11                                             |
|                                                        | Recognising the good things about their brother or sister with a disability | 5                                              |
|                                                        | Family closeness                                                            | 3                                              |
|                                                        | Recognising the good things about their family                              | 6                                              |
|                                                        | Family communication                                                        | 4                                              |
|                                                        | Responsibility                                                              | 7                                              |
|                                                        | Treatment by others compared to sibling                                     | 7                                              |
|                                                        | Amount of attention received from parents                                   | 4                                              |
|                                                        | Relationship with brother or sister with a disability                       | 8                                              |
|                                                        | Behaviour of brother or sister with an intellectual disability              | 5                                              |
|                                                        | Feeling different from others                                               | 6                                              |
|                                                        | Concerns/worries                                                            | 9                                              |
|                                                        | Family Stress                                                               | 4                                              |
|                                                        | Feelings about their brother or sister/ disability                          | 7                                              |
|                                                        | Part 2: Social Life                                                         | Opportunities arisen from sibling's disability |
| Proud feelings about brother or sister with disability |                                                                             | 3                                              |
| Explaining sibling's condition to others               |                                                                             | 6                                              |
| Missed social opportunities                            |                                                                             | 5                                              |
| Friends' feelings                                      |                                                                             | 5                                              |
| Treatment of brother or sister by others               |                                                                             | 3                                              |
| Embarrassment                                          |                                                                             | 4                                              |
| Teasing                                                |                                                                             | 5                                              |
| Missed social activities                               |                                                                             | 10                                             |
| Disruption of time with friends                        |                                                                             | 3                                              |
| Treatment by others                                    |                                                                             | 10                                             |
| Others' understanding                                  | 5                                                                           |                                                |

### 3.4 Participants

#### 3.4.1 Recruitment of Participants

Participants were older teenage siblings (12-17 years) of children with an intellectual disability. They were accessed via the Disability Services Commission of Western Australia (DSC). The definition of intellectual disability, which deems individuals eligible for services at the DSC, is as follows:

...substantial limitations in present functioning. It is characterised by significant sub average intellectual functioning [IQ <70], existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Intellectual disability manifests before age 18, (DSC, 1997, p. 4).

Recruiting siblings of children registered with DSC ensured a consistent diagnosis of intellectual disability. It also meant that participants in the expert validation process came from families that were currently receiving services from a disability organisation and therefore had ongoing care needs.

The Disability Services Commission database initially identified families in Western Australia who had a child (17 years of age or younger) with an intellectual disability. Whilst the database was unable to identify which of these families had older siblings between 12 and 17 years, 1818 clients had an identification number which allowed them to be linked to a state database which contained information on the age and gender of siblings for families

registered up until 1995. The Maternal and Child Research Database - Sibshiplinkage was developed by the TVW Child and Health Institute for Research in Perth, Western Australia. Thus, where a linkage identification number was present, an employee of TVW Child and Health Institute of Research collated this information. Eight hundred and eighty-two families were identified as having a sibling between the ages of 12 and 17 years through this process. There were 376 families who could not be linked to the database, due to being born after 1995 or not having an identification number for linkage. Thus, all of these families were contacted to determine whether they had an older sibling in the age range.

The sample identified by this process included 1258 families. This number represented the total population of siblings in Western Australia, available for the research project in 2001. As this project required two studies, requiring four samples of siblings, to ensure that there was an equal probability for families to participate in each stage of the present study, the list of potential participants established from the above procedure was randomly sorted into four lists of approximately 314<sup>2</sup> participants that represented each of the four stages of research. These four stages included the three in Study 1 and the one in Study 2.

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<sup>2</sup> As new potential families were identified in subsequent years, the lists for Stages 2 and 3 of Study 1 and Study 2 were supplemented

Three hundred and fourteen families were selected through this procedure to be contacted about Stage 1 of the project. Forty-seven of these families, however, had unknown addresses, leaving 267 families to be contacted.

Families who were contacted were asked to return a form indicating if they had a child eligible to participate in the project regardless of whether or not they wished to participate. In addition, follow-up phone calls were made to families who did not respond (see Data Collection, 3.5, pg. 55). In total, 210 families responded, leaving 57 families where no contact was made. Of these 210 families, 88 indicated that they had a sibling eligible to participate in the research whilst 122 families indicated that they did not. In total 36 eligible<sup>3</sup> siblings participated, resulting in a response rate of 11% (including all families invited to participate) and a participation rate (including only those families eligible to participate) of 41%. This is represented in Figure 3.2 below.

Eight of the eligible participants, however, did not complete the questionnaire according to instructions (they rated items rather than ranked them), invalidating their responses and thus their data were removed from data analyses.

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<sup>3</sup> There were 45 siblings who returned completed questionnaires, though 9 were younger than their sibling with a disability. As the present research is only concerned with older siblings, the 9 younger siblings who sent back completed questionnaires, were excluded from this stage of the research. The 2 twins remained in the sample.

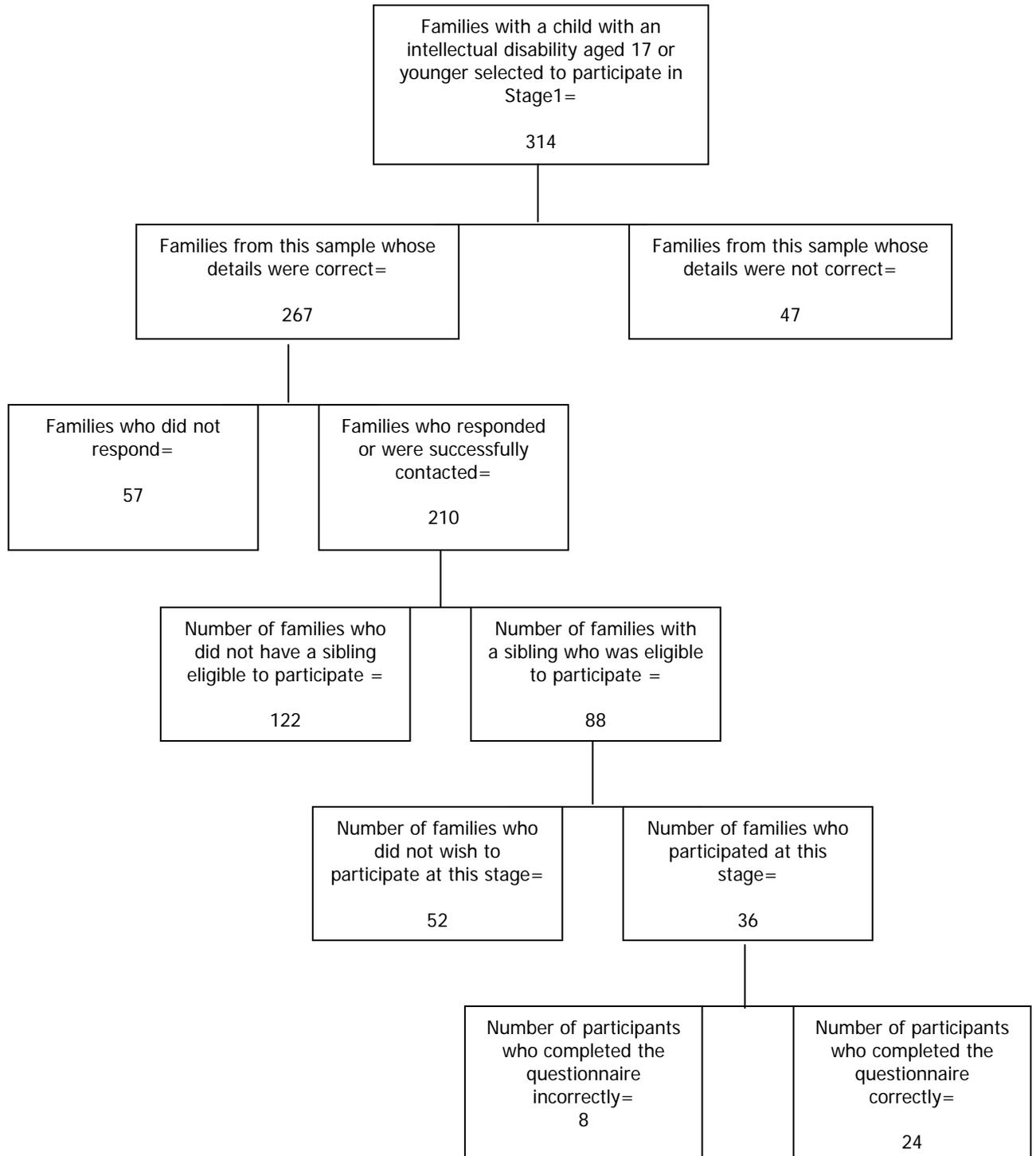


Figure 3.2 Diagram of participation rates stage 1, study 1.

### 3.4.2 General Characteristics

Participants were 24<sup>4</sup> siblings of children with an intellectual disability (9 males and 15 females), with 22 being older than their sibling with an intellectual disability and 2 being twins. They were aged between 12 and 17 years of age ( $M = 15.13$ ,  $SD = 1.82$ ). These participants were all living at home with at least one natural birth parent in the Perth Metropolitan Area, the Outer Perth Metropolitan Area or Country areas of Western Australia.

### 3.4.3 Characteristics of the Child with an Intellectual Disability

The children with an intellectual disability in the participants' families were aged between 4 and 15 years ( $M = 11.50$ ,  $SD = 2.87$ ), with 12 male and 10 female and 2 not recorded. One of the participants was a stepsibling of the child with an intellectual disability whilst the remaining 23 participants shared the same biological parents as their disabled sibling. A large proportion of cause of the child's intellectual disability was unknown (52.38%). Down syndrome, Rett syndrome, Fragile X, Language Delay, and Autism were some of the diagnoses recorded by parents of children with known causes.

In order to determine the amount of support each child required, parents were asked to rate the level of support their child required from 1 (occasional support in two or more areas) to 4 (support in all areas of daily living). The overall support scores ranged from 1 to 4 and had a mean of 2.67 ( $SD =$

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<sup>4</sup> There were 45 siblings of children with an intellectual disability who returned completed questionnaires. However, 9 of these siblings were younger than their sibling with a disability and 8 participants incorrectly completed the questionnaire leaving 24 remaining participants.

1.17), with 33.3% ( $n = 8$ ) of parents reporting that their child required support in all areas.

Fifteen of these participants went to the same school as their brother or sister with a disability, at some stage of their lives. The time spent at school together ranged from less than 1 year to 8 years ( $M = 1.54$ ,  $SD = 2.02$ ).

However, none of the participants were currently attending the same school as their brother or sister with an intellectual disability.

#### 3.4.4 Parental Characteristics

The age of the mothers ranged from 33 to 54 years ( $M = 42.56$ ,  $SD = 4.99$ ) and the age of the fathers ranged from 33 to 64 years ( $M = 44.71$ ,  $SD = 6.94$ ). Sixteen mothers were married, whilst 4 were separated and 4 were divorced. Seventeen fathers were reported to be married, 3 separated and 1 divorced. Seven of these families reported receiving assistance from an agency other than the Disability Services Commission. The educational levels reported for mothers and fathers are outlined in Table 3.3.

Table 3.3

#### *Education Levels of Mothers and Fathers in Stage 1, Study 1*

| Parent  | Yr 10 | Yr 11 | Yr 12 | TAFE* | University | Other | Missing |
|---------|-------|-------|-------|-------|------------|-------|---------|
| Mothers | 6     | 2     | 2     | 3     | 7          | 2     | 2       |
| Fathers | 5     | 2     | 3     | 3     | 8          | 0     | 3       |

\*TAFE = Technical and Further Education Institution

### **3.5 Materials**

A questionnaire package consisting of an introduction letter, an information sheet for parents and children, a participation form (indicating whether they had siblings eligible to participate), a demographic questionnaire and a copy of Version 1 of the measure was sent to families (see B Appendices). The demographic questionnaire included details of sibling age, the presence of any other disabilities or health problems, parental age, level of education, last paid employment, extent of disability, family structure and whether the family receives additional support (see Appendix B6). The Version 1 measure consisted of 150 items and 26 subscales as described above. Participants were asked to rank order items in each subscale in order of importance.

A plain envelope was provided for participants to seal their completed questionnaire in and a stamped, self-addressed Curtin University of Technology envelope was provided to return the questionnaire and participation form to the researcher.

### **3.6 Procedure**

A questionnaire package was sent to all families. Parents were asked to complete the participation form and demographic questionnaire. In order to determine the validity of items and issues covered by Version 1 of the measure, participants were asked to 1/ rank order items in each subscale of

the measure in order of importance for them and; 2/ indicate the relevance of issues covered by each subscale. Families were given one month to respond to the invitation. Teenagers who participated in the study were given the opportunity to enter a draw to win a movie ticket prize. Consent was assumed from return of the completed demographics form and questionnaire. Approximately one month after the initial questionnaire package was sent a research assistant affiliated with the DSC-WA conducted follow-up phone calls to families who had not responded to the initial invitation. The purpose of these phone calls was to find out if the family was eligible to participate and to ensure that they received an information package. The phone calls also served as a reminder, and allowed parents to express any concerns they may have had about their child participating. Those who could not be contacted by telephone were sent an additional letter (see Appendix B4) and questionnaire package. All families who indicated interest in the research and a wish to receive the results were sent the results after the preliminary analysis had been completed.

### 3.6.1 Ethical Considerations

Prior to the recruitment of participants, ethics approval was obtained from Curtin University of Technology, Disability Services Commission of Western Australia and the TVW Child and Health Institute Research Committee. Participation in all stages of the present study was entirely voluntary. As participants were below 18 years of age, parents/caregivers were sent the

invitations to participate in the study rather than the participants themselves (see Appendix B1).

Participants and their parent/caregiver were informed that they may withdraw from the study at any time with no impact on the services they receive from the Disability Services Commission of Western Australia or any other organisation or agency (see Information Sheets in Appendices B2 and B3). In order to ensure the confidentiality of families identified through the Disability Services Commission and TVW Child and Health Institute, only an allocated staff member at each organisation accessed the information. Thus, the researcher accessed no information of a personal nature. In addition, questionnaire packages were provided to the Disability Services Commission by the researcher. A staff member then personally addressed each introduction letter and envelope and forwarded these packages to families. Families who wished to participate then contacted the researcher directly, with consent assumed from the return of a completed demographic form and questionnaire. Participants were also provided with a plain envelope, in which to seal their completed questionnaire before handing it to their parent to send in the self-addressed envelope. This ensured confidentiality of participants' answers from their parents.

Each case was assigned an identification number. Identifying information (such as consent forms) was kept separate from the questionnaires. This

was explained to the parents/ guardians of the participating children prior to participation (see Information Sheets in Appendices B2 and B3).

### **3.7 Results**

#### 3.7.1 Data Analyses

SPSS for Windows (Version 11.5) was used for data analyses. Descriptive statistics such as the mean, median and mode were calculated for each item's ranking to determine the overall importance and relevance of items for participants. Next, the frequencies of participants' ratings of the subscales were computed. These results were used to decide which items and subscales should remain in the item pool and which items or subscales should be removed or further explored in Stage 2.

#### 3.7.2 Missing Data for Items

There was a large amount of missing data (it ranged from 0-54% for individual items) in some of the completed questionnaires. This may have occurred for a number of reasons:

- Participants only completed sections they felt were relevant for them
- Participants did not read instructions thoroughly before completing the questionnaire
- The total item pool was too long for this age-group

As questionnaires were completed anonymously, participants could not be contacted to correct missing data. Although research aims to minimise missing data it is believed that in the development of a measure, missing data, in and of itself, may provide valuable information. Therefore, when deciding on which items required further exploration, those items with high missing data were considered.

### 3.7.3 Missing Data for Issues

Along with the high amount of missing data for items, there was a high level of missing data (12.5% - 20.8% across subscales) for participants' selection of subscales. Any questionnaires where all subscales were left blank were deemed as missing data. Qualitative responses indicated that some participants found the questionnaire too long, hence this may have contributed to the high amount of missing data.

### 3.7.4 Modification of the Item Pool

According to the principles of theoretical keying items that do not seem likely to tap into the construct they are measuring should be removed from the item pool (Shackelton & Fletcher, 1984). Thus, the descriptive statistics of the item rankings helped identify which items were most relevant and important to participants. The mode of each item provided information on the ranking most typically given by participants, the mean of each item indicated the average ranking given, while the median identified the middle of the ranking range. In addition the range was explored and those items

displaying a very low range were considered as having low utility. In line with the multi-method approach (Wicker, 1989), the importance of the item as determined from previous empirical research was also considered when making difficult decisions about whether items should stay, be removed or further explored.

Participants were asked to rank order items in each subscale in order of importance. The following inclusion/exclusion criteria were used: Items that were consistently rank ordered as important (i.e. the item had a low mode, mean and/or median) remained in the item pool, items consistently rank ordered as unimportant (i.e. the item had a high mode, mean and/or median) though had high literature support (reported in numerous research papers) were selected for further validation in Stage 2, items consistently rank ordered low on importance (i.e. the item had a low mode, mean and/or median) and had low range or high amount of missing data compared to other items in the subscale were considered for removal from the item pool.

#### *3.7.4.1 Items Removed*

Overall 10 items were removed at this stage of measurement development. The items along with descriptive statistics are presented in Table 3.4.

Table 3.4

*Items Removed from the Pool, Stage 1 (N = 24)*

| Item                                                                              | No.items<br>in section | Mode  | Mean | Median | Missing | Range |
|-----------------------------------------------------------------------------------|------------------------|-------|------|--------|---------|-------|
| P1A11 "Having ..... in our family has made me a more honest person"               | 11                     | 10    | 8.59 | 9.00   | 2       | 7     |
| P1C1 "My family is closer since..... was born"                                    | 3                      | 3     | 2.32 | 2.00   | 2       | 2     |
| P1I4 "I don't feel as if I can stand up to ..... because he/she has a disability" | 8                      | 8     | 5.63 | 6.00   | 5       | 7     |
| P1L3 "I wish I could go to the same school as ....."                              | 9                      | 8     | 5.35 | 6.00   | 3       | 4     |
| P1N6 "I am worried that I too may get what ..... has"                             | 7                      | 7     | 5.32 | 6.00   | 5       | 6     |
| P2A2 "My teacher knows about ...and is really understanding"                      | 5                      | 5     | 4.41 | 5.00   | 7       | 4     |
| P2I2 "I look after at.....school"                                                 | 10                     | 9, 10 | 6.33 | 8.00   | 12      | 9     |
| P2I5 "Checking on ..... at school leaves me with less time to spend with friends" | 10                     | 5, 10 | 7.55 | 8.00   | 13      | 5     |

*3.7.4.2 Items Selected for Further Exploration in Stage 2*

Overall 27 items were selected for further exploration by participants in Stage 2. The list of items and descriptive statistics are presented in Tables 3.5 and 3.6.

Table 3.5

*Items Selected for Further Exploration – Part 1 Family Life (N = 24)*

| Item                                                                                                                        | No. items<br>in section | Mode | Mean | Median | Missing | Range |
|-----------------------------------------------------------------------------------------------------------------------------|-------------------------|------|------|--------|---------|-------|
| P1A5 "I have learnt to speak out on behalf of my family"                                                                    | 11                      | 11   | 7.29 | 8.00   | 3       | 9     |
| P1B5 "My relationship with ..... is better than my friends relationship with their brother/sister/s"                        | 5                       | 5    | 3.33 | 4.00   | 0       | 4     |
| P1C3 "We do more as a family, I think, because of the way.... is"                                                           | 3                       | 3    | 2.14 | 2.00   | 2       | 2     |
| P1D2 "My family gets to meet lots of people through the agencies where ..... gets cared for"                                | 6                       | 6    | 4.35 | 5.00   | 1       | 5     |
| P1F5 "I wish I didn't have to take care of ..... so much of the time"                                                       | 7                       | 4, 7 | 4.87 | 5.00   | 1       | 6     |
| P1G2 "Sometimes I think my parents love ... more than me"                                                                   | 7                       | 7    | 4.95 | 5.50   | 4       | 6     |
| P1G7 "My parents have to spend so much money on the needs of ..., that there isn't much money left over for my needs/wants" | 7                       | 7    | 4.55 | 5.00   | 2       | 6     |
| P1H4 "My accomplishments are usually overlooked by my parents"                                                              | 4                       | 4    | 2.77 | 3.00   | 2       | 3     |
| P1I1 "I argue with ..... more than I think other brothers/sisters do"                                                       | 8                       | 8    | 5.75 | 6.00   | 4       | 7     |
| P1J5 "My family and I are always tired because..... often wakes up in the middle of the night"                              | 5                       | 5    | 3.75 | 5.00   | 4       | 4     |
| P1K6 "My family misses out on opportunities that other families get to do such as going on holidays together"               | 6                       | 6    | 4.17 | 6.00   | 1       | 5     |
| P1L4 "I wish ... could go to a school closer to our home"                                                                   | 9                       | 7    | 4.65 | 5.00   | 4       | 7     |
| P1N3 "I feel like I caused ..... to be the way he/she is"                                                                   | 7                       | 7    | 5.44 | 6.00   | 6       | 6     |
| P1N7 "I feel guilty that I am healthy and ..... is not"                                                                     | 7                       | 7    | 4.50 | 5.50   | 4       | 6     |

Table 3.6

*Items Selected for Further Exploration – Part 2 Social Life (N = 24)*

| Item                                                                                                | No. items<br>in section | Mode  | Mean | Median | Missing | Range |
|-----------------------------------------------------------------------------------------------------|-------------------------|-------|------|--------|---------|-------|
| P2A1 "People are curious about.....'s disability and ask me lots of questions"                      | 5                       | 5     | 3.70 | 5.00   | 4       | 4     |
| P2A3 "I have more friends because of ....."                                                         | 5                       | 4     | 4.15 | 4.00   | 4       | 3     |
| P2B3 "I am proud when I am out with my family"                                                      | 3                       | 3     | 2.48 | 3.00   | 3       | 2     |
| P2C6 "I make up stories about ..... because I'm too embarrassed to tell the truth"                  | 6                       | 6     | 5.39 | 6.00   | 6       | 4     |
| P2D4 "I would never bring my girl/boyfriend/best friend home because of....."                       | 5                       | 5     | 4.06 | 5.00   | 6       | 4     |
| P2E5 "Many friends don't come over because of ....."                                                | 5                       | 5     | 4.65 | 5.00   | 4       | 3     |
| P2G3 "I pretend I don't know ..... when he/she does embarrassing things"                            | 4                       | 4     | 3.35 | 4.00   | 4       | 2     |
| P2H1 "People tease me about....."                                                                   | 5                       | 5     | 4.22 | 5.00   | 6       | 4     |
| P2I1 "I can't play the sports I want to"                                                            | 10                      | 10    | 6.33 | 6.00   | 9       | 9     |
| P2J2 "My parents always want me to include ..... in my plans with friends"                          | 3                       | 3     | 2.70 | 3.00   | 4       | 4     |
| P2K9 "My teachers treat me differently when they find out I have a bro/sis with special needs"      | 10                      | 10    | 7.44 | 8.00   | 8       | 8     |
| P2K10 "Other people may think that there is something wrong with me because ..... has a disability" | 10                      | 9, 10 | 7.76 | 9.00   | 7       | 9     |
| P2L2 "I feel as if I am the only person in the world in this particular situation"                  | 5                       | 4     | 3.95 | 4.00   | 5       | 3     |

3.7.5 Importance of the Issues Presented

After completing each part of the measure, participants were asked to indicate the importance of subscales on a 3-point scale (important/not

importance/unsure). The frequencies of these selections are listed in Tables 3.7 and 3.8.

Table 3.7

*Importance of Subscales in Part 1 - Family Life (N = 24)*

| Subscale                                                                                  | Subscale | Important | Not important | Unsure | Frequency of missing |
|-------------------------------------------------------------------------------------------|----------|-----------|---------------|--------|----------------------|
| Learning from their brother or sister's disability                                        | A        | 50%       | 4.2%          | 25%    | 20.8%                |
| Recognising the good things about their brother or sister with an intellectual disability | B        | 41.7%     | 12.5%         | 25%    | 20.8%                |
| Family closeness                                                                          | C        | 29.2%     | 25%           | 25%    | 20.8%                |
| Recognising the good things about their family                                            | D        | 50%       | 16.7%         | 12.5%  | 20.8%                |
| Family communication                                                                      | E        | 33.3%     | 33.3%         | 12.5%  | 20.8%                |
| Responsibility                                                                            | F        | 37.5%     | 20.8%         | 20.8%  | 20.8%                |
| Treatment compared to brother or sister                                                   | G        | 33.3%     | 29.2%         | 16.7%  | 20.8%                |
| Amount of attention received from parents                                                 | H        | 4.2%      | 50%           | 25%    | 20.8%                |
| Relationship with brother/sister with an intellectual disability                          | I        | 41.7%     | 25%           | 12.5%  | 20.8%                |
| Behaviour of brother/sister with an intellectual disability                               | J        | 29.2%     | 20.8%         | 29.2%  | 20.8%                |
| Feeling different from others                                                             | K        | 29.2%     | 25%           | 25%    | 20.8%                |
| Concerns/worries                                                                          | L        | 37.5%     | 20.8%         | 20.8%  | 20.8%                |
| Family stress                                                                             | M        | 29.2%     | 33.3%         | 16.7%  | 20.8%                |
| Feelings about brother or sister/disability                                               | N        | 33.3%     | 25%           | 25%    | 16.7%                |

Table 3.8

*Importance of Subscales in Part 2 – Social Life (N = 24)*

| Subscales                                             | Subscale | Important | Not important | Unsure | Frequency of missing |
|-------------------------------------------------------|----------|-----------|---------------|--------|----------------------|
| Opportunities arisen from disability                  | A        | 25%       | 41.7%         | 20.8%  | 12.5%                |
| Proud feelings about brother/sister with a disability | B        | 54.2%     | 12.5%         | 20.8%  | 12.5%                |
| Explaining brother/sister's condition to others       | C        | 33.3%     | 54.2%         | 0%     | 12.5%                |
| Missed opportunities                                  | D        | 33.3%     | 50%           | 4.2%   | 12.5%                |
| Friends' feelings                                     | E        | 25%       | 41.7%         | 20.8%  | 12.5%                |
| Treatment of brother/sister by others                 | F        | 37.5%     | 33.3%         | 16.7%  | 12.5%                |
| Embarrassment                                         | G        | 45.8%     | 29.2%         | 12.5%  | 12.5%                |
| Teasing                                               | H        | 33.3%     | 37.5%         | 16.7%  | 12.5%                |
| Missed social opportunities                           | I        | 16.7%     | 54.2%         | 16.7%  | 12.5%                |
| Disruption of time with friends                       | J        | 29.2%     | 33.3%         | 25%    | 12.5%                |
| Treatment by others                                   | K        | 37.5%     | 37.5%         | 12.5%  | 12.5%                |
| Other's understanding                                 | L        | 37.5%     | 20.8%         | 29.2%  | 12.5%                |

3.7.6 Least Important Subscales

For Part 1 – Family Life, the subscale that was least important for the validation sample was the amount of attention received from their parents, with only one participant (4.2%) rating this subscale as important to them, while half of the participants rated it as unimportant. Missing out on social opportunities was found to be the least important subscale in Part 2 - Social Life for participants with only 16.7% of participants deeming it to be important.

### **3.8 Qualitative Responses**

Participants were also asked to list any additional issues that were important to them and/or make a comment about the questionnaire. No new issues were raised, however nine of the 24 participants made additional responses with some related to the questionnaire itself and other more general comments. The themes that emerged from the qualitative responses indicated that the teenage siblings found the questionnaire too long and some participants had difficulty rank ordering items that were not relevant to them at all. Stages 2-3 of the measure development addressed these difficulties.

### **3.9 Summary**

Stage 1 of the first study involved the development of an extensive item pool (150 items) that was then validated by a sample of teenage siblings. The validation process indicated that ten items were unimportant (the mode, mean and/or median was high). These items were then excluded from the item pool. In addition, 27 items that were consistently rank ordered as unimportant though had high literature support were selected for further validation in Stage 2. The resulting instrument consisted of 140 items divided into 26 subscales – 14 of these covering the perceived effect of disability on siblings' family lives and 12 of these covering the perceived effect of disability on siblings' social lives. This first stage in the development

of this instrument served to reduce the size of the measure and enhance its relevance to the population.

## *Chapter 4: Study 1: Measure Development Stage 2*

### **4.1 Aim**

Stage 2 involved further validation and reduction of items with another sample of participants to ensure the issues covered in the measure were representative of the issues teenage siblings face in today's society. Second, this study aimed to further validate and reduce the item pool. The aim was to produce a shorter, more refined measure. In this chapter the methods used to further develop the measure will be presented, including a description of participants, instruments and procedures, followed by the results of Stage 2. The results are presented in terms of issues raised by participants and further item analysis.

### **4.2 Participants**

#### 4.2.1 Recruitment of Participants

##### *4.2.1.1 Pilot group*

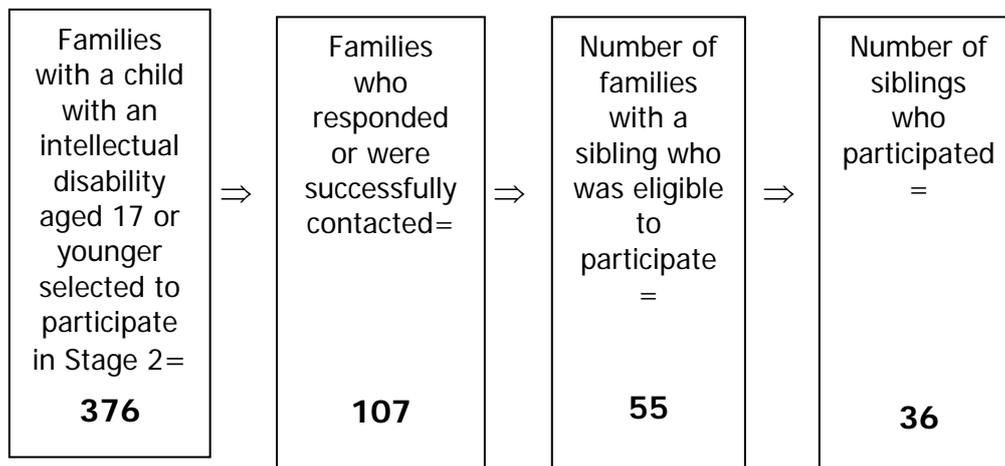
Prior to running the main focus groups, a pilot group was run with 5 siblings of children with a disability recruited through Landsdale Farm School. The aim of this pilot group was to test the protocol for the focus groups. This pilot group was conducted in a small living room at a local Farm school in the Perth Metropolitan area over a sibling weekend camp. These children were aged from 12 to 15 years (2 males, 3 females) from families of children with a range of disabilities including both physical and intellectual disabilities.

Parents of these participants were sent information sheets and consent forms prior to the sibling camp weekend.

#### *4.2.1.2 Focus Groups*

Participants for the focus groups were accessed via the Disability Services Commission of Western Australia. Three hundred and fourteen families were randomly chosen from the population identified from the DSC and Maternal and Child Health databases in Stage 1 (see Section 3.4.1, p. 49). To increase participant numbers, ten additional families (who had a child with an intellectual disability 17 years of age or younger and a sibling between 12 and 17 years of age) were recruited through the Stepping Stones program - a program designed for children with disabilities and behaviour problems; 44 additional families were contacted via Identity WA - a private disability organisation providing services for families in Western Australia; and eight additional families were contacted through the Goldfields Individual and Family Support Inc. in order to conduct a country group. These families were not identified by previous search methods and demographically they did not differ from the original sample of potential participants. This resulted in a sample pool of 376 potential families. Families contacted about Stage 2 of Study 1 were asked to return a form indicating if they had a child eligible to participate in the project. One hundred and seven families responded, whilst 269 families did not. Of the families who responded, 30 wished to participate (6 families had 2 children eligible to participate), 25 indicated that they were eligible but did not wish for their child to participate and 52

families did not have children fitting the criteria of the study. This resulted in a response rate of 8%. Whilst this rate appears very low, over half of the families who responded indicated that they did not have children eligible to participant. Of the 55 families who did respond and were eligible, 30 families (with 36 siblings in total) chose to participate, giving a participation rate of 55%. Adolescent siblings who were available on the specified days formed the focus groups. Recruitment is summarised in the figure below:



*Figure 4.1* Diagram of participation rates stage 2, study 1.

#### 4.2.2 General Characteristics

Participants were 36 older siblings (23 female, 13 male) of children with an intellectual disability. They were aged between 12 and 17 years of age ( $M = 14.20$ ,  $SD = 1.68$ ). These participants formed 6 focus groups (Group 1 = 3 males, 5 females, Group 2 = 2 males, 3 females, Group 3 = 1 male, 3

females, Group 4 = 1 male, 5 females, Group 5 = 1 male, 4 females, Country group = 5 males, 3 females). The participants in the main groups were from 22 families living in the Perth Metropolitan Area or the Outer Perth Metropolitan Area, while the country groups were from eight families living in the Kalgoorlie/Boulder region.

#### 4.2.3 Characteristics of the Child with an Intellectual Disability

The children with an intellectual disability in the participants' families were aged between 2 and 15 years of age ( $M = 10.01$ ,  $SD = 3.50$ ), with 14 males, 14 females and 2 unknown. Three of the participants were stepbrothers or sisters of the child with an intellectual disability. Three children were in a blended family, but had the same parents as their sibling with a disability. The remaining participants had the same biological parents as their sibling with an intellectual disability. The cause of the child's intellectual disability was unknown for approximately 25% of participants. Of those that had known causes, 25% were Down syndrome. Other known causes included Epilepsy, Autism, Hypoxia and Prenatal Infection.

Parents were asked to indicate the level of support the child with a disability in the family required on a 4-point scale as in Stage 1: occasional or limited support, support in two or more areas, or support in all areas. The overall support scores ranged from 1 to 4 and had a mean of 2.86 ( $SD = 1.12$ ), with 28.6% ( $n = 8$ ) of parents reporting that their child required support in all areas.

Fifteen of these participants went to the same school as their brother or sister with a disability at some stage of their lives. The time spent at school together ranged from less than 1 to 6 years ( $M = 1.46$ ,  $SD = 1.78$ ).

However, only one of these participants was attending the same school as their brother or sister with an intellectual disability at the time of participation.

#### 4.2.4 Parental Characteristics

The age of the mothers ranged from 34 to 52 years ( $M = 43.29$ ,  $SD = 5.46$ ) and the age of the fathers ranged from 27 to 56 years ( $M = 45.50$ ,  $SD = 5.44$ ). Twenty-five of the mothers and fathers were married, whilst 2 were in a defacto relationship and 1 was divorced (figures for mothers and fathers were identical). Eight of these families reported receiving additional assistance from another agency. The distribution of education level of mothers and fathers are outlined in Table 4.1.

Table 4.1

#### *Education Levels of Mothers and Fathers in Stage 2, Study 1*

| Parent  | Yr 10 | Yr 11 | Yr 12 | TAFE* | University | Other | Missing |
|---------|-------|-------|-------|-------|------------|-------|---------|
| Mothers | 7     | 1     | 6     | 2     | 11         | 1     | 0       |
| Fathers | 4     | 2     | 3     | 6     | 12         | 0     | 1       |

\*TAFE = Technical and Further Education institution

### 4.3 Materials

An information pack was sent to all potential participants. The information pack consisted of an introduction letter, an information sheet for parents and teenagers and a form to indicate if their family was eligible to participate (see C Appendices). Participants and their caregivers who responded and were eligible to participate were then sent a confirmation letter and additional information sheet explaining what was involved in this stage of the research (see Appendix C4). Primary caregivers were asked to complete a demographic questionnaire and consent form indicating their permission for their child to participate (see Appendices C5 and C6). This demographic questionnaire included details of sibling age, the presence of any other disabilities or health problems, parental age, level of education, last paid employment, extent of disability, family structure and whether the family receives additional support.

Mileage reimbursement and parking costs were provided to families of children attending the Perth groups to cover the costs of attending the focus groups and children participating received a double movie ticket as a token of appreciation (the country group was run at the location of a sibling group and thus no special trip to the focus group was needed).

Sheets of A2 paper were used in the focus groups to present the focus group questions and record field notes. A tape recorder was used to record the discussions of each focus group.

## 4.4 Procedure

When the final participants arrived at the location of the focus groups, their primary caregiver was asked to complete the demographic questionnaire and consent form. Families of children participating in the Perth groups were provided with their mileage reimbursement and parking costs and all children participating received their movie tickets at this time (the country group received other benefits as a result of attending the sibling camp such as sweet treats and outings).

### 4.4.1 Organisation of the Focus Groups

A Clinical Psychology Trainee and a Psychologist Registrar facilitated the focus groups. The main focus groups were all held in a group room at the School of Psychology at Curtin University of Technology, over the school holidays or on a Saturday. The country group was conducted on a sibling camp weekend run by a private disability organisation in the rural mining town of Kalgoorlie, Western Australia. The aim of this group was to ensure that the issues experienced by siblings in rural areas were adequately represented in the measure. The country group was located in a large group room on the campgrounds.

A research assistant was also present at the focus group to answer any parent questions regarding the project and to witness parents signing consent forms. Parents of the groups in Perth (as the country group was run over a weekend camp with no parents present) were invited to watch "It's a

Long Road" (a documentary for families of children with a disability) in another room whilst their child was participating in the focus groups, although four of the groups of parents preferred to exchange information and to share their stories with each other.

#### 4.4.2 Focus Group Protocol

A protocol for the focus groups was developed and tested with the pilot group. Feedback from the facilitators and participants at the pilot group resulted in slight changes to the group protocol. This protocol was then adhered to for the main focus groups (see Appendix D for both protocols).

Each focus group was semi-structured with questions revolving around the two areas of interest - perceived effect of disability on family and social life. The second half of the focus groups revolved around further exploration of items selected in Stage 1.

The focus groups began with an introduction and general rapport building. The facilitator explained the overall goal of understanding the effect of disability on the family and social life for teenage siblings of children with an intellectual disability. Participants were asked for their verbal consent to audiotape the discussion and confidentiality was explained. The facilitator then asked participants how having a sibling with an intellectual disability had impacted on their family life. Whilst participants discussed this, the co-facilitator listed the comments and issues raised onto large A2 sheets pinned

to a board at the front of the room. After discussion was exhausted, the co-facilitator summarised and fed back the information generated by the participants to determine the accuracy of the summary. This process was then repeated with participants discussing the impact on their social lives.

The second half of the focus group sessions involved participants providing further feedback on some items selected for Version 2 of the measure. The items were presented to participants on sheets of A2 paper. To ensure serial position order effects of items did not influence participants, the order of the items was randomly chosen for each of the focus groups. Participants were informed that the items were “things that some teenagers have said to us about what it is like for them being a brother or sister of a child with special needs.” The facilitator then asked participants to indicate the relevance/importance of the comments for themselves and determine how relevant/important each idea was for the *group as a whole*.

Participants were asked how they were feeling after the completion of the group and a follow-up phone call was made to all families to answer any concerns or questions they had regarding the research. A summary of the results was sent to families who indicated interest in the results of the focus groups sessions.

### 4.4.3 Field Notes

The list of comments and issues recorded by the co-facilitator during each focus group served as the field notes. To further ensure that the list of issues raised during the focus groups was reliable, a research assistant completed a full transcript of one of the focus groups tapes picked at random. This transcription was then given to an independent rater (a person who was not present at the focus groups) who analysed the transcript and identified the issues raised. This analysis was then compared to the field notes completed during that focus group. The number and content of themes from the researcher and independent rater were identical.

## **4.5 Results**

### 4.5.1 Data Analyses

Thematic analysis “involves the inductive identification of codes from the data” (Liamputtong & Ezzy, 2005, p.259). Liamputtong and Ezzy argue that there can be many pitfalls associated with analysing qualitative data with computers and thus researchers should make an “informed choice” about the role computers may play in the analysis of their data. For example, Barry (1998) reports that researchers using computer-assisted analyses may be distanced from their data and some treat qualitative data as quantitative data. While there are ways of overcoming these pitfalls, Liaputtong and Ezzy argue that researchers are often able to achieve their task without the use of computer-assisted programs. As extensive field notes were collected during

the focus groups, and the reliability of the notes had been checked by participants in the focus group sessions and by an independent rater, it was decided that computer-assisted data analysis would be redundant in the present stage.

Aronson (1994) describes the pragmatics involved in thematic analysis. The process described by Aronson provided direction for the present analysis. The process involved collecting data, audiotaping and transcribing the data, identifying themes and subthemes, obtaining feedback from participants and building an argument for the choice of themes by referring back to the literature. The list of themes discussed in the focus groups served as the basic data for thematic analysis. The researcher identified and coded themes, which were discussed in the focus group sessions and generated the frequencies of themes raised using SPSS for Windows (Version 11.5). In total 24 issues were identified across all the groups. The lists of issues raised by the participants in the focus group sessions were then compared to Version 1 of the measure.

Response to the items on the A2 sheets served as the basic data for item analysis. The researcher tabulated the importance/relevance of items for each group. The criteria for inclusion/exclusion were as follows: items that were deemed as important/relevant by at least two groups remained in the item pool, whilst items that were viewed as not relevant/unimportant by 4/5 of

the groups were removed from the measure, and items that were unclear to some groups were reworded.

#### 4.5.2 Main Themes Emerging from the Focus Groups

Nineteen of the identified themes directly corresponded to subscales included in Version 2 of the measure. The themes presented in the focus groups are listed in Table 4.2 along with the number of groups that discussed the theme. These themes will then be discussed in detail.

Table 4.2

#### *Existing Themes Presented in the Groups*

| Theme                                                                | No. of Groups Discussed |
|----------------------------------------------------------------------|-------------------------|
| Recognising good things about their brother/sister with a disability | 6                       |
| Behaviour of brother/sister with a disability                        | 6                       |
| Treatment of brother/sister by others                                | 6                       |
| Feeling different from others                                        | 6                       |
| Friends' feelings                                                    | 5                       |
| Feelings about brother or sister/disability                          | 5                       |
| Others' understanding                                                | 4                       |
| Amount of attention received from parents                            | 5                       |
| Explaining brother/sister's condition to others                      | 4                       |
| Responsibility                                                       | 4                       |
| Embarrassment                                                        | 4                       |
| Disruption of time with friends                                      | 3                       |
| Teasing                                                              | 3                       |
| Relationship with brother/sister with an intellectual disability     | 2                       |
| Family stress                                                        | 2                       |
| Learning from their brother or sister's disability                   | 2                       |
| Concerns/worries                                                     | 1                       |
| Treatment by others                                                  | 1                       |
| Missed social opportunities                                          | 1                       |

*Recognising good things about their brother or sister with an intellectual disability.* All of the groups discussed the good things about their brother or sister with a disability. One sibling commented: "he's generally nice. People with Downs...with most disabilities are genuinely nice - you're wearing a new top and he'll say, *oh, nice top* or *looking nice* or I'll put some perfume on *smells nice.*" Comments from other siblings were similar, for example, "[He] says hello to everybody - [is] very friendly, talks to them about everything" and "[She's] very popular, sweet, hugs people, laughs with people, she's cute".

*Behaviour of brother or sister with an intellectual disability.* For many participants, the behaviour of their brother or sister was a source of confusion and stress. Stories were told of participants' brother or sister engaging in behaviour that baffled them, such as "laughing" or "crying for no reason". Others described their siblings' behaviour as disruptive, for example, when their sibling did not let them go to sleep and one explained that her sibling "likes videos [and] if [I] change the TV she throws tantrums."

*Treatment of brother or sister by others.* How others treat their brother or sister was a concern for many siblings across all of the focus groups. One participant described feeling "angry and defensive when people say things" about her brother, while another explained "some people say she looks *weird*... I want to stick up for her". Many felt that their sibling was treated differently from others: "People treat her differently because she has Down

syndrome”, “When we take her out...people stare. Sometimes they ask questions and [I have to] explain.”

*Friends' feelings.* Participants in the five main groups raised the topic of how their friends felt about their brother or sister with an intellectual disability. While some participants spoke of their friends having positive feelings, for example, “[my] friends really like him – give him lots of attention”, others reported more challenging experiences with friends, for example, one participant explained that she had “one bad friend [who] didn't like disabled people.”

*Feeling different from others.* Feeling different from others was a concern for many. One sibling explained that they “can't go out spontaneously” and “we don't go on holidays much”, another even stated that they were “unsure of what *normal* behaviour is”. Only one participant made the comment in a group that they felt “like normal.”

*Feelings about brother or sister/disability.* Along with discussing how they feel compared to others, many discussed their feelings towards their sibling. Feelings raised by many included annoyance and frustration over their sibling's behaviour. One sibling explained that he had to constantly repeat information to his sister – “you try and tell her something and you have to tell her about 20 times before she gets it sometimes...it's frustrating.”

*Others' understanding.* Similar to feeling different compared to others, many participants felt that others didn't understand what life was like for them. Participant responses included: "Friends don't get why you can't go out with them. [They] haven't ever experienced it themselves", "People try and sympathise with you when you tell them about your sib [but they] don't understand much" and "People always ask, *Is she getting better?* - they don't understand that it changes all the time."

*Amount of attention received from parents.* The issue of attention was one freely discussed by a number of participants and prompted comments from some of the quieter members in the focus groups. While some siblings thought that attention was evenly distributed amongst all children in their family, others believed that their sibling received more attention - "[it was] strange when he was born.... [we lost] attention.... [it's] still like that". Interestingly, however, many of the participants who believed their sibling received more attention tended to accept this. For example, one sibling commented, "My sibling gets lots of attention - [but it's] normal as he is the youngest", while another reflected, "My sibling gets more attention - when I was little [I was] jealous, but now [I] understand."

*Explaining brother or sister's condition to others.* Some siblings found it easy to explain to friends about their sibling's disability whilst others commented, "explaining can be hard... doing it all the time is annoying". It was noted that many siblings who didn't understand their sibling's disability

or the associated symptoms consequently found it difficult to explain their sibling's condition to their friends. For example, one sibling remarked-"I didn't know how to explain it- [I] knew how she acted, not why."

*Responsibility.* The issue of increased responsibilities for siblings was discussed by many of the participants in the focus groups. While some siblings appeared to resent their extra responsibilities that they had in their families, some appeared to understand. Participant comments included: "Others rely on me when something happens, for example, when friends come over and she won't go away", "Someone always has to be with [my] sister...it's frustrating" and "I look after her when my parents are away... I don't mind unless I had plans."

*Embarrassment.* Embarrassment is an issue experienced by all brothers and sisters at some stage, however it appeared to be more pronounced for some of the teenagers in the focus groups. One sibling discussed how her parents had just purchased a large van to accommodate her sister's wheelchair and she thought it really stood out and was embarrassing. Another talked of her embarrassment surrounding her sister's delayed development -"She only stopped playing with dolls last year so she used to take her dolls everywhere and that was a bit embarrassing. She's older [but] she has the mind of a younger child."

*Disruption of time with friends.* Disruption of time with their friends was an issue raised by various participants in the focus groups with one sibling explaining that her brother “annoys us when friends are over - he won’t go away” and another recalled how his sibling “follows me and a friend” at school and “won’t listen if I say go away”.

*Teasing.* Teasing was a point of concern for some siblings who recalled various people making rude or inappropriate comments to them regarding their sibling and/or their disability. For example, one sibling reported getting “upset when friends tease” and another explained that his brother “always get into fights - others hint to you [and I] stop them before they say anything”. It is important to note, though, that many of the participants who told stories of others teasing them, were recalling stories from when they were young children, and thus, it didn’t appear to be a present concern.

*Relationship with brother or sister with an intellectual disability.* Many believe that the sibling relationship between a child with an intellectual disability and other children in the family will not have the same characteristics of a “typical” sibling relationship. Accordingly, some siblings raised this issue in the focus groups, however other participants reported having a “close relationship” and “normal brother play fights” with their sibling with a disability.

*Family stress.* Stress was discussed by only a small number of participants in the groups. One sibling stated of her sister “she was quite violent when younger [it was] hard on mum” however that it was “getting easier now she is older”, while contrary to this, another sibling stated that stress “doesn’t impact” on her family at all. It is important to note that discussion of family stress was limited to the impact on parents – no siblings discussed the impact on the family as a whole.

*Learning from brother or sister’s disability.* The topic of what they had learnt from their sibling’s disability was raised in two of the groups. The participants that raised this topic commented on how having a brother or sister with a disability makes them “understand how lucky I am”, and “less judgmental”. One participant argued that other teenagers his age “don’t know how to express their feelings the way we do”, and another described how having a sibling with a disability has made her more of a caring person as she helps another girl with a disability on the bus everyday.

*Concerns/worries.* A few participants discussed the concerns they have about their sibling with an intellectual disability. Many were concerned about the treatment of their sibling by other people. For example, one sibling recalled of his brother – “I saw how helpless he could be - that people didn’t care - [it was] disgusting” and another explained their sibling who had no friends at school “[it’s] sad seeing him around school”.

*Treatment by others.* While the treatment of their sibling by others was a concern for some participants, others believed that having a brother or sister with a disability has affected the way people treat them. For example, one stated that others - "stare at you or ignore you" and another explained "a friend used to use my brother to get at me in an argument. I told her I could break her legs - so she would know what it feels like".

*Missed Social Opportunities.* While missed social opportunities is an issue identified by many researchers as an effect of disability on siblings, it was a topic discussed by only one sibling in the country group. This sibling discussed how they "can only have friends on weekends" however, no other sibling added their experiences of missing out on social opportunities.

#### 4.5.3 Other Themes to Emerge from the Focus Groups

In addition to the above themes, there were five themes that were raised in the focus groups that were indirectly related to subscales included in Version 2 of the measure. These included: responsibilities associated with a specific condition; difficulty communicating with a sibling; sickness; strategies to deal with sibling; and changes in family outings.

*Responsibilities associated with a specific condition.* One sibling discussed how her sister was "hard to take around" as she was in a wheel chair. This appears to be an additional responsibility due to the specific condition of the child and thus related to the "Responsibility" subscale.

*Difficulty communicating.* Difficulty communicating with their sibling was a topic raised by some in the groups. One sibling discussed how his brother “can’t speak [he just] shakes his head – points his head – you have to work out what he wants” and another explained that their sibling “can’t walk or talk but smiles sometimes”. These siblings spoke of the frustration of not being able to understand their sibling and in turn their sibling understanding them. This subtheme impacts on and thus relates to the “Relationship with brother/sister with an intellectual disability” subscale.

*Sickness.* Many children with an intellectual disability often have other disabilities or illnesses associated with their condition. This was the case for at least two siblings who explained that their sister was often admitted to hospital and that this interfered in such things as going on holidays. It is believed that this is related to the “Missed Social Opportunities” subscale.

*Strategies to deal with sibling.* Two siblings discussed strategies they used to deal with their brother or sisters disability in one of the focus groups. One sibling discussed a chart reward system that her family had put in place and used with her sibling, whilst another explained “when she’s annoying I put on the Wiggles<sup>5</sup> or something for her”. While specific strategies children use to deal with their sibling has not been addressed in the literature, it can be considered to be related to the “Responsibility” subscale.

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<sup>5</sup> The “Wiggles” is a popular children’s television show

*Changes in family outings.* Last, two siblings discussed changes in their family outings due to their sibling's disability. These changes included taking an extra change of clothes out because their sibling always spills things on their clothes and the sibling who explained how their family had purchased a large van to accommodate their sibling's disability. This may contribute to siblings "Feeling Compared to Others" and therefore, is associated with this subscale.

#### 4.5.4 Unidentified Themes

Seven subscales covered in Version 2 of the measure were not supported by focus group data. These subscales included: closeness of family; recognising good things about family; family's communication; treatment compared to a sibling; proud feelings about sibling; missed opportunities; and opportunities arising from sibling's disability. However, possible explanations for this may be sample bias. In the case of research with minors, this occurs on two levels- 1/ with the parents/caregivers of the children, and 2/ with the children themselves. Families who participated in Stage 2 of Study 1 were interested in sibling needs and enthusiastic about aiding research in this area. Hence, these families may be more sensitive to the needs of their other children by treating family members as equally as possible, ensuring siblings maintain a "normal" lifestyle, are relatively close and have good communication. However, this does not account for why proud feelings about their sibling did not arise or siblings' ability to recognise the good things about their family. Perhaps siblings can recognise these

effects when directly asked, however, they do not readily come to mind as an effect of disability on their lives without prompting. Without directly asking siblings why these issues were not raised it cannot be assumed that these issues are not relevant. Hence, this information was used in collaboration with validity information collected in Stage 1 to determine inclusion in the measure.

#### 4.5.5 Country Group

The aim of including a country group was to check that the subscales covered in the measure included those relevant to siblings in city areas, as well as country areas. Ten separate themes were discussed by siblings in the country groups with nine of these also discussed by siblings in the Perth focus groups. The only separate theme identified for siblings in the country groups, was missing out on social opportunities. This topic is already covered in the measure.

#### 4.5.6 Item Analysis

The aim of the second half of the focus group discussion was to gain further feedback on items selected in Stage 1. A table listing the number of groups disagreeing with an item or reporting that the item was unclear is presented below in Table 4.3 and 4.4.

Table 4.3

*Item Analysis Part 1 - Family Life*

| Item                                                                                                         | No. of groups<br><i>not</i><br><i>important</i> | No. of groups<br><i>unclear</i> |
|--------------------------------------------------------------------------------------------------------------|-------------------------------------------------|---------------------------------|
| A5, "I have to learned to speak out on behalf of my family"                                                  | 0                                               | 3                               |
| B5, "My relationship with... is better than my friends relationship with their....."                         | 0                                               | 0                               |
| C3, "We do more as a family, I think, because of the way ..... is"                                           | 2                                               | 0                               |
| D2, "My family gets to meet lots of people through the agencies where ..... is cared for"                    | 0                                               | 0                               |
| F5, "I wish I didn't have to take care of.....so much of the time"                                           | 1                                               | 0                               |
| G2, "Sometimes I think my parents love.... more than me"                                                     | 4                                               | 0                               |
| G7, "My parents have to spend so much \$ on the needs of ..... that there isn't much left over for my needs" | 4                                               | 0                               |
| H4, "My accomplishments are usually overlooked by my parents"                                                | 2                                               | 1                               |
| I1, "I argue with ..... more than I think other brothers and sisters do"                                     | 4                                               | 0                               |
| J5, "My family and I are always tired because .....often wakes up in the middle of the night"                | 2                                               | 0                               |
| K6, "My family misses out on opportunities that other families get to do such as going on holidays together" | 1                                               | 0                               |
| L4, "I wish ..... could go to a school closer to our home"                                                   | 5                                               | 0                               |
| N3, "I feel like I caused ..... to be the way he/she is"                                                     | 4                                               | 0                               |
| N7, "I feel guilty that I am healthy and .... is not"                                                        | 4                                               | 0                               |

Table 4.4

*Item Analysis Part 2 - Social Life*

| Item                                                                                                    | No. of groups<br><i>not</i><br><i>important</i> | No. of groups<br><i>unclear</i> |
|---------------------------------------------------------------------------------------------------------|-------------------------------------------------|---------------------------------|
| A1, "People are curious about.....'s disability and ask me lots of questions"                           | 0                                               | 0                               |
| A3, "I have more friends because of ....."                                                              | 3                                               | 0                               |
| B3, "I am proud when I am out with my family"                                                           | 0                                               | 0                               |
| C6, "I make up stories about ..... because I am too embarrassed to tell the truth"                      | 3                                               | 0                               |
| D4, "I would never bring my best friend/girlfriend/boyfriend home because of ....."                     | 5                                               | 0                               |
| E5, "Many friends don't come over because of....."                                                      | 5                                               | 0                               |
| G3, "I pretend I don't know ..... when he/she does embarrassing things"                                 | 3                                               | 0                               |
| H1, "People tease me about....."                                                                        | 2                                               | 0                               |
| I1, "I can't play the sports I want to"                                                                 | 4                                               | 0                               |
| J2, "My parents always want me to include ..... in my plans with friends"                               | 4                                               | 0                               |
| K9, "My teachers treat me differently when they find out I have a Brother or sister with special needs" | 3                                               | 0                               |
| K10, "Other people may think that there is something wrong with me because ...<br>has a disability"     | 4                                               | 0                               |
| L2, "I feel as if I am the only person in the world in this particular situation"                       | 3                                               | 0                               |

Of the 27 items, participants in at least one focus group agreed that 14 items were important, while 11 items were not found to be important/relevant for participants in at least four focus groups. Furthermore, two items were found to be unclear. Items which four or more focus groups deemed as not important were excluded and items that were unclear to any groups, were modified. Section 4.5.8.2 (pg. 96) presents and discusses these items.

#### 4.5.7 Linking Stage 1 and 2 Results

It was expected that most of the themes identified in the literature and covered in the measure would be raised in the focus groups. However, only a small number of literature-identified themes were raised in the focus groups. This could be due to literature being out-of-date with today's society, the diversity of each population or due to the focus groups being non-representative. Alternatively it could be due to the predominant use of parent-report measures in the past. It was expected that there would be differences in responses between Stage 1 and 2 due to the different modes of data collection, with some siblings finding it easier to answer such questions anonymously on a questionnaire, and others being more comfortable discussing such issues face-to-face. The results of Stage 2 were combined with the quantitative results of Stage 1. These results were then compared to the amount of literature support for each subscale. This determined which items and subscales should remain in the next version. The percentage of participants who rated a subscale as being important is presented in Table 4.5 along with the number of focus groups where the theme was identified.

Table 4.5

*Comparison of Stage 1 and Stage 2 Data*

| Subscale                                                         | Stage 1 Important (%) | Stage 2 No. of Groups Discussed |
|------------------------------------------------------------------|-----------------------|---------------------------------|
| Learning from sibling's disability                               | 50%                   | 33.3%                           |
| Recognising good things about sibling                            | 41.7%                 | 100%                            |
| Family closeness                                                 | 29.2%                 | 0%                              |
| Recognising good things about family                             | 50%                   | 0%                              |
| Family communication                                             | 33.3%                 | 0%                              |
| Responsibilities                                                 | 37.5%                 | 66.7%                           |
| Treatment compared to sibling                                    | 33.5%                 | 0%                              |
| Attention received from parents                                  | 4.2%                  | 83.3%                           |
| Relationship with brother/sister with an Intellectual disability | 41.7%                 | 66.7%                           |
| Behaviour of sibling                                             | 29.2%                 | 100%                            |
| Feeling compared to others                                       | 29.2%                 | 100%                            |
| Concerns about sibling                                           | 37.5%                 | 16.7%                           |
| Stress on family                                                 | 29.2%                 | 33.3%                           |
| Feelings about sibling                                           | 33.3%                 | 83.3%                           |
| Opportunities arising from disability                            | 25%                   | 0%                              |
| Proud feelings about sibling                                     | 54.2%                 | 0%                              |
| Explaining sibling's disability to others                        | 33.3%                 | 66.7%                           |
| Missed opportunities                                             | 33.3%                 | 0%                              |
| Friends feelings about sibling                                   | 25%                   | 83.3%                           |
| Treatment of sibling by others                                   | 37.5%                 | 100%                            |
| Embarrassment                                                    | 45.8%                 | 66.7%                           |
| Teasing                                                          | 33.3%                 | 50%                             |
| Missed social opportunities                                      | 16.7%                 | 16.7%                           |
| Disruption of time with friends                                  | 29.2%                 | 50%                             |
| Treatment by others                                              | 37.5%                 | 16.7%                           |
| Understanding from others                                        | 37.5%                 | 66.7%                           |

Subscales that represented themes identified as important for more than 25% of participants in Stage 1, or the theme was raised by participants in Stage 2 and had high literature support, were included in Version 3 of the measure. Subscales that were deemed important by participants in only one stage and had a low amount of literature support were excluded.

As can be seen in Table 4.5 "Recognising Good Things About Sibling", "Responsibilities", "Relationship with Sibling", "Behaviour of Sibling", "Feeling Compared to Others", "Concerns About Sibling", "Stress on Family", "Feelings About Sibling", "Explaining Sibling's Disability to Others", "Treatment of Sibling by Others", "Embarrassment", "Teasing", "Disruption of Time with Others" and "Treatment By Others" were all deemed important by more than 25% of participants in Stage 1 and raised by participants in Stage 2. In total, 24 of the 26 subscales were rated as important by at least 25% of participants in Stage 1 or raised by participants in at least one group. Thus, these subscales were included in Version 3 of the measure.

The "Family Closeness", "Recognising Good Things About Family", "Family Communication", "Treatment Compared to Sibling" and "Proud Feelings About Sibling" were rated as important by more than 25% of participants in Stage 1; however, participants in Stage 2 did not raise the topics.

"Opportunities Arising From Disability" was deemed as important by only 25% of participants in Stage 1 and not raised by participants in Stage 2. As

this theme had a low level of literature support, it was excluded from Version 3 of the measure.

The theme of stress on the family has strong support in the literature. Two participants in separate focus groups raised this topic however only in relation to their parents experiencing stress. For example, one participant who raised the issue discussed how stress had affected her family when they were younger and another said it wasn't as much a problem as they thought it would be. Furthermore, this theme was only discussed in relation to stress on the parents, not the family as a whole or the stress that is experienced by the individual sibling. As the focus group data revealed that the crux of this issue was related to parental stress rather than stress on the family as a whole (the aim of the subscale), it was excluded.

Last, it is interesting to note that "attention from parents" was a theme raised by most of the focus groups; however, it was deemed as important by less than 5% of participants in Stage 1. However, most of the participants who raised this matter in the focus groups understood why their sibling received more attention.

#### 4.5.8 Modifications to the Measure

##### *4.5.8.1 Subscales Removed or Modified*

Two subscales were removed from the questionnaire. These were "Stress on Family" (Part 1, M) and "Opportunities Arising from Disability" (Part 2, A).

Further modifications were made by combining two subscales. The issue of “recognising the good things in their family” was raised by only one of the participants in the focus groups while 50% of participants in Stage 1 deemed the subscale covering this issue to be important. “Recognising the good things about their sibling” however, was rated highly (41.7%) in Stage 1 and discussed by all focus groups in Stage 2. As both of these were theoretically similar and it was believed that recognising good things about family *includes* their ability to recognise the good things about their sibling, the decision to combine these two subscales was made.

#### *4.5.8.2 Items Removed or Modified*

After the above summaries of results were complete, some items were removed or modified. Items that at least four of the focus groups disagreed with were removed, while items that participants stated were unclear were modified in line with the feedback. A list of these items is presented in Table 4.6.

Table 4.6

*Items Removed From the Measure*


---

| Item          |                                                                                                          |
|---------------|----------------------------------------------------------------------------------------------------------|
| Part 1 G, 2   | "Sometimes I think my parents love ..... more than me"                                                   |
| Part 1, G, 7  | "My parents have to spend so much \$ on the needs of ..... that there isn't much left over for my needs" |
| Part 1, I, 1  | "I argue with ..... more than I think other brothers and sisters do"                                     |
| Part 1, L, 4  | "I wish ..... could go to a school closer to our home"                                                   |
| Part 1, N, 3  | "I feel like I caused ..... to be the way he/she is"                                                     |
| Part 1, N, 7  | "I feel guilty that I am healthy and .... is not"                                                        |
| Part 2, D, 4  | "I would never bring my best friend/girlfriend/boyfriend home because of ....."                          |
| Part 2, E, 5  | "Many friends don't come over because of ....."                                                          |
| Part 2, I, 1  | "I can't play the sports I want to"                                                                      |
| Part 2, J, 2  | "My parents always want me to include ..... in my plans with friends"                                    |
| Part 2, K, 10 | "Other people may think that there is something wrong with me because ... has a disability"              |

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There were two items which participants in the focus groups stated were unclear to them and thus required modification.

The first item modified was in Part 1, A, 5:

"I have learned to speak out on behalf of my family" which was modified to "I have learned to speak up for my family"

The second item modified was in Part 1, H, 4:

“My accomplishments are usually overlooked by my parents” which was modified to “My achievements are usually noticed by my parents”.

The removal and modification of the above items and subscales left 123 items in Version 3 of the measure from the original 150-item pool. Based on the high percentage of missing data in Stage 1, the response type and layout of the measure was made user-friendlier. The rating of items in the measure was modified to a four-point likert scale. Items were presented in subscales to ensure that the measure was user-friendly, however, in order to ensure that the reliability of the measure was not influenced by this layout in Stage 3, a version with random placement of items, was sent to half of the potential participants.

Finally, the measure was made more attractive with comic pictures. This allowed for additional instructions to be relayed through the comic figures.

#### **4.6 Summary**

Focus groups were run in Stage 2 of Study 1 to ensure that the items and issues presented by the measure represented the “effect of disability” on teenage siblings in today’s society. As expected, many of the issues raised in

Stage 2 supported the results of Stage 1. The comparison of Stage 1 and 2 data allowed issues that were not raised in the focus groups, to be combined with more evidence regarding its relevance/importance to teenage siblings in our society before removing an issue prematurely. This process allowed for the further elimination of issues and items, which were not relevant or important for siblings. The result was a 123-item measure with 24 subscales, displaying good content and face validity ready to be assessed for its psychometric properties in Stage 3.

## *Chapter 5: Study 1: Measure Development Stage 3*

### **5.1 Aim**

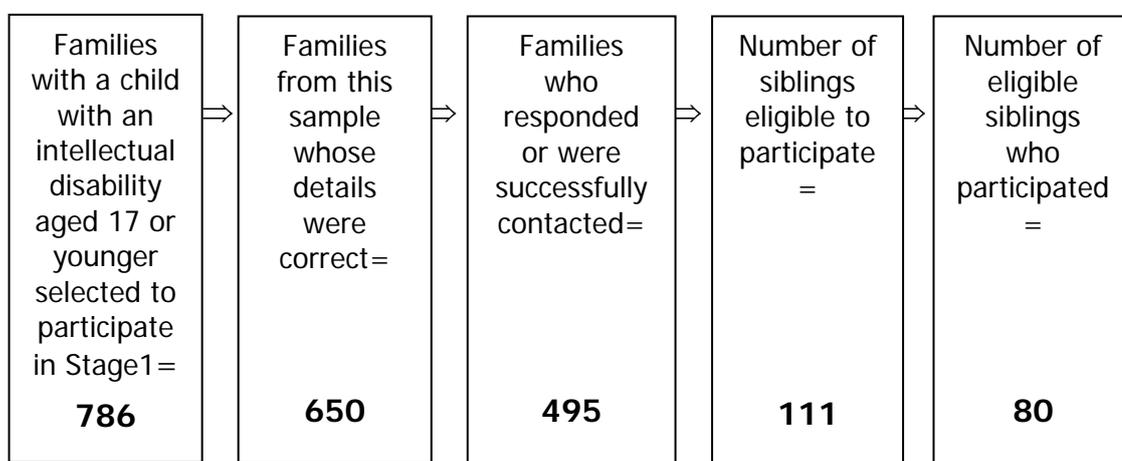
The first two stages of Study 1 involved the development and reduction of an item pool for the Perceived Effect of Disability measure and validation of the items and subscales covered in the measure. The measure was then modified and refined accordingly. The aim of Stage 3 then was to investigate the reliability and the factorial validity of the final version of the Perceive Effect of Disability measure. The chapter begins by describing the methods used including the recruitment and description of participants, the materials and procedure used for Stage 3. The results of the psychometric analyses are then produced along with a discussion of the results.

### **5.2 Participants**

#### 5.2.1 Recruitment of Participants

Participants that had been identified in the process outlined in Chapter 3 (Section 3.4.1, pg. 49), and had been randomly assigned to Groups 3 and 4 were invited to participate in *both* Study 1 - Stage 3 and Study 2. In addition, any potential participants who had been identified since the original process through DSC were included. To ensure a sufficient sample size several attempts were also made to access participants from other states in Australia however the ethical process required lengthy periods before potential participants could be accessed. In total, 786 families formed

Groups 3 and 4, however 136 of these families had unknown or incorrect contact details. Four hundred and ninety five of these families responded either by sending back information or through follow-up phone calls conducted by research assistants through DSC, whilst 109 families did not respond. Of the families responding, 111 had children eligible to participate while 384 did not. Thirty-one of the 111 eligible families did not wish their child to participate. Reasons for non-participation including: a death in the family, experiencing another stressful life event or the teenage sibling not being interested in completing the questionnaire. Eighty of the eligible<sup>6</sup> children participated in Stage 3, giving a total response rate of 12% (of the 650 contacted) and a participation rate of 72% (including all those known eligible to participate). This is represented in the Figure 5.1:



*Figure 5.1* Diagram of participation rates stage 3, study 1.

<sup>6</sup> In total 105 completed questionnaires were returned, however 25 had to be excluded from the analyses as the children who had completed them were out of the age-range or were younger than their sibling with a disability.

### 5.2.2 General Characteristics

The participants were 80 older siblings of children with an intellectual disability (32 males and 48 females;  $M = 15.07$  years,  $SD = 1.56$ ). They were from 71 families in Western Australia living in the Perth Metropolitan Area, Outer Perth Metropolitan Area or Country areas. Seventy-six of the participants lived at home with at least one natural birth parent whilst three children were adopted and one was in a foster home. Seventy-eight of these participants had only one sibling with a disability, whilst two had two siblings with a disability. Thirty-four of these participants completed two copies of the measure approximately six weeks apart and thus formed the participant sample for the test-retest analyses conducted on the measure.

### 5.2.3 Characteristics of the Child with an Intellectual Disability

The children with an intellectual disability in the participants' families were aged from 4 months to 16 years ( $M = 10.54$ ,  $SD = 3.64$ ), with 50 male, 26 female and 4 not recorded. One participant was a stepsibling of the child with an intellectual disability, whilst eight children were in blended families.

The cause of the child's intellectual disability was unknown for approximately 40% of children. The diagnoses included 22.5% related to disorders in the PDD spectrum and 15% Down syndrome. Other known diagnoses included Dyspraxia, Cerebral Palsy, Cri Du Chat, Rett Syndrome, Prader-Willi, Nieman-Pick "Type-C", Marden Walker syndrome, Dandy Walker syndrome, West Syndrome, Tetrasomy 18P and Hydrocephalus.

The level of support the child required ranged from 1 (occasional support in two or more areas) to 4 (support in all areas of daily living), with a mean of 2.67 ( $SD = 1.17$ ). Just over 31% ( $n = 25$ ) of parents in this stage reported that their child required "occasional support in two or more areas".

Forty-eight of the participants had gone to the same school as their brother or sister with a disability at some stage of their lives. The time spent at school together ranged from less than one year to eight years ( $M = 1.40$ ,  $SD = 0.49$ ). Only 11 of these participants were attending the same school as their brother or sister with an intellectual disability at the time of participation.

#### 5.2.4 Parental Characteristics

The age of the mothers ranged from 32.75 to 60.83 years ( $M = 41.97$ ,  $SD = 5.22$ ) and the age of the fathers ranged from 33.50 to 63.25 years ( $M = 44.57$ ,  $SD = 6.55$ ). The distribution of marital status for mothers and fathers is presented in Table 5.1 and the distribution of education levels outlined in Table 5.2. Twenty-four percent of families (19 families) reported receiving additional assistance from another agency.

Table 5.1

*Marital Status of Parents*

| Parent  | Married | Divorced | Separated | Defacto | Single | Not specified |
|---------|---------|----------|-----------|---------|--------|---------------|
| Mothers | 58      | 5        | 8         | 7       | 1      | 1             |
| Fathers | 59      | 2        | 6         | 4       | 2      | 7             |

Table 5.2

*Education Levels of Mothers and Fathers in Stage 3, Study 1*

| Parent  | Yr 10 | Yr 11 | Yr 12 | TAFE* | University | Other | Missing |
|---------|-------|-------|-------|-------|------------|-------|---------|
| Mothers | 30    | 9     | 5     | 12    | 15         | 8     | 1       |
| Fathers | 23    | 1     | 3     | 23    | 15         | 6     | 9       |

\*TAFE = Technical and Further Education institution

### 5.3 Materials

A questionnaire package (see E Appendices) was sent to all families contacted about Stage 3. This package included an introduction letter; an information sheet for parents and teenage participants; a form to indicate if their family was eligible to participate; a demographic questionnaire; a copy of Version 3 of Perceived Effect of Disability the measure; a plain envelope for sibling participants to seal the questionnaire in; and lastly a stamped self-addressed Curtin University of Technology envelope to return the questionnaires to the researcher. The demographic questionnaire included details of sibling age, the presence of any other disabilities or health problems, parental age, level of education, last paid employment, extent of

disability, family structure and whether the family receives additional support. As per Stage 1, consent was assumed from the return of completed questionnaires.

### 5.3.1 Version 3 of the Perceived Effect of Disability (PED) Measure

The third version of the PED measure consisted of 123 items across 23 subscales. Two copies of the measure were printed. Copy A (see Appendix E8), presented the items in a random order and Copy B (see Appendix E9) presented items ordered in their respective subscales.

## **5.4 Procedure**

Families were mailed a questionnaire package and then given three weeks to respond to the invitation and return the questionnaire package. Half of the families were sent Copy A of the measure and the other half were sent Copy B of the measure. Approximately one month after the questionnaire package was sent, a research assistant affiliated with DSC conducted follow-up phone calls to families who had not responded. These phone calls determined the eligibility of families and whether they received an information package (See Appendices F1 and F2 for the protocol and record sheet). The follow-up phone calls to families increased the participation rate from 56% ( $n = 62$ ) to 72% ( $n = 80$ ).

Parents/caregivers were asked to complete the demographic form and teenage siblings were asked to complete the PED measure. Siblings who were only interested in participating in this Stage 3 of Study 1 completed the measure a second time approximately 6 weeks later in order to determine the test-retest reliability of the measure. All children who completed a second questionnaire at Stage 3 received a small box of chocolates as a token of appreciation for being involved. Siblings who sent back completed questionnaires and indicated interest in participating in Study 2, were sent a thank you letter and told that they would be contacted at a later date regarding the next stage of the project.

## **5.5 Internal Consistency**

### 5.5.1 Data Analyses

In total, 35 eligible random versions and 45 eligible sectioned versions of the PED measure were returned. The data were entered into SPSS for Windows (Version 11.5) and then the dataset was checked to ensure each entry was within the eligible range for each item. There was only a small amount of missing data (a maximum of 5/80 participants missing any given item), which was missing randomly across items. Any values that were out of the possible range were converted to missing data (as recommended by Tabachnick & Fidell, 1989). Tabachnick and Fidell believe that two important factors need to be considered prior to data analysis: Sample size and, more importantly, the pattern of the missing data. Given that the missing data

were randomly distributed, missing data were replaced with an estimate of the sample average for that item.

The internal consistency of items and subscales were separately calculated for each version of the questionnaire (random and sectioned) using Cronbach's alpha. In order to further reduce the item pool for the following exploratory factor analysis, discriminability analysis was then conducted. This process involves removing items that have a low correlation (and therefore reduce the estimate of reliability) with their respective scale (Kaplan & Saccuzzo, 2005).

### 5.5.2 Results

Both versions of the question demonstrated high internal consistency (Sectioned version Cronbach's  $\alpha = .934$ , Random version Cronbach's  $\alpha = .949$ ). No further comparisons between versions were made as it was important that items and subscales were reliable across both versions of the measure to ensure that participants' responses were not dependent upon the presentation of items. Thus, any items and subscales that had low reliability across either version were removed. Kaplan and Saccuzzo (1997) state that reliability coefficients ranging from .70 to .80 are acceptable. A Cronbach's alpha value of .70 was used as the cut-off rather than the general cut-off of .80 as a higher cut-off may have eliminated nearly all of the subscales. The internal consistencies of each subscale were re-calculated, and any further items, which decreased the reliability of their subscale, were removed.

Seventy-four items were removed through this process. In total, 49 items (32 items in Part 1, Family Life and 17 items in Part 2, Social Life), which proved reliable across both versions over this process, remained in the measure at Version 4.

## **5.6 Factorial Validity**

### 5.6.1 Data Analyses

Separate exploratory factor analyses (EFAs) were conducted on each part of the measure to determine whether any of the remaining subscales could be combined into higher order subscales. EFA is viewed by many as the first stage in instrument development. Fronman (2001) argues, "given sufficient theoretical preparation, EFA can provide the first objective test of an idea", (p. 7). Confirmatory Factor Analyses are then conducted on a set of independent data in order to confirm an EFA solution. Given the difficulty with finding participants for this study, only Exploratory Factor Analyses were conducted. As the present study was more concerned with producing scales of summed items rather than uncovering the latent constructs that underlie the scales, Principal Components Analyses (PCAs) were conducted (Tabachnick & Fidell, 1996).

Due to a low participant-to-item ratio, separate PCAs were conducted on the two parts of the measure. Part 1 covered the perceived effect of disability on siblings' family lives; Part 2 covered the perceived effect on their social

lives. Orthogonal (Varimax) rotations were used to more easily interpret the factors<sup>7</sup> (Tabachnick & Fidell, 1989). Varimax rotations are the most common method of rotation (Tabachnick & Fidell). This method maximises the variance of the squared loadings thus aiding the interpretations (Rencher, 1995). Varimax is recommended as the default option by Tabachnick and Fidell.

Recommendations for EFA sample sizes vary considerably. Many recommend a minimum of 5 participants per item and 100 participants in total (e.g., Fronman, 2001). Comrey (1988) recommends, "A sample size of 200 is reasonably good for ordinary factor-analytic work with 40 or fewer variables", (p. 759). Furthermore, Kline (1986) recommends a minimum of 200 cases in order to have a low standard error rate when conducting reliability studies on tests. Given the limitations of applied research and this population in particular, the present sample size of 80 participants only allowed for the most modest of these recommendations. The present project exhausted all potential participants in Western Australia and therefore no further participants from this population were available.

If only a small sample size is available, many recommend the use of more conservative criteria in the analyses (e.g., Pal & Chaudhury, 1998). The present study followed conservative criteria for factor retention used by Pal and Chaudhury in their preliminary validation of a parental adjustment

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<sup>7</sup> The more familiar term "factor" will be used in the following chapters instead of the more accurate term "components"

measure for families of disabled children. Factors with eigenvalues greater than 2 were retained and only items with factor loadings greater than 0.5 were extracted.

### 5.6.2 Assumption Testing

Shapiro-Wilks and Lilliford analyses were conducted on each individual item prior to conducting the two factor analyses in order to assess whether the normality assumption had been met. Both of these analyses were significant ( $p < .05$ ) indicating violations to these assumptions. This suggests that the data were not normally distributed. Thus, Spearman's Rank Order Correlations, a 'non-parametric alternative' (Coakes & Steed, 2003), were used in the PCA correlation matrix rather than Pearson's  $r$ .

### 5.6.3 Part 1

Principal Components Analyses (PCAs) with orthogonal (Varimax) rotation were performed on Version 4 of the measure; Part 1 - Family Life consisting of 32 items.

This analysis resulted in 2 factors with Eigenvalues greater than 2. The first factor included 15 items with loadings greater than 0.5. The items related to positive influence of disability on siblings. Factor 2 included eight items with loadings greater than 0.5. The items related to siblings' perception of family differences. In total seven items did not load on any factor over 0.5 and

thus were removed. As items H1, H2, H4 were negatively correlated with the other items forming Factor 1, these items were reverse coded.

Another PCA with orthogonal rotation was conducted on the remaining 25 items in Part 1. Two additional items had factor loadings less than 0.5 so were removed. This resulted in a third PCA being conducted on the remaining 23 items. This final PCA produced two factors with all items with factor loadings greater than 0.5 (see Table 5.2). The correlation matrix for the final factor analysis is located in Appendix G1.

The integrity of the subscales remained throughout the three PCAs with subscales forming two overall factors (Subscales, A,C and H forming Factor 1 and subscales E and J forming Factor 2). Thus the PCAs supported the thematic analysis. In the final PCA, Factor 1 included 15 items with factor loadings greater than 0.5 with an eigenvalue of 7.18 and accounting for 31.24% of the variance. The items in this factor represented positive influence of disability. Factor 2 included 8 items with an eigenvalue of 4.17 and accounting for 18.12% of variance. The items in Factor 2 dealt with family differences. Together both factors accounted for 49.35% of variance in total. These factors were subsequently defined as Positive Influence of Disability (Factor 1) and Family Differences (Factor 2).

The Kaiser-Meyer-Olkin Measure and Bartlett's Test for Sphericity were used to determine the factorability of the correlation matrix, (Coakes & Steed

2003). The final PCA had a Kaiser-Olkin Measure of Sampling Adequacy of .80 and a significant Bartlett's Test of Sphericity, which suggested that the correlation matrix generated was suitable for the analyses.

Cronbach's alpha reliability coefficients for internal consistency of the 23 items were determined for the revised version of Part 1. These revealed high internal consistency for Part 1 (Part 1 Total = .87) along with high internal consistency for each factor (Factor 1 = .91, Factor 2 = .84).

Table 5.3

*Factor Loadings of Items in Part 1*

| Item                                                                                                   | <i>Factor Loadings</i>                       |                                |
|--------------------------------------------------------------------------------------------------------|----------------------------------------------|--------------------------------|
|                                                                                                        | Factor 1<br>Positive Influence of Disability | Factor 2<br>Family Differences |
| Living with ____ has taught me a lot about people that are different                                   | .570                                         |                                |
| My family has learnt a lot about life from ____'s disability                                           | .522                                         |                                |
| ____ has taught me so much about what life really means                                                | .733                                         |                                |
| I think having ____ in our family has made me a more patient person                                    | .600                                         |                                |
| I think having ____ in our family has helped me understand more about other people's feeling           | .629                                         |                                |
| _____ makes our family life more fun!                                                                  | .654                                         |                                |
| My family life is more interesting because of _____                                                    | .636                                         |                                |
| I like doing things with _____                                                                         | .805                                         |                                |
| I admire _____                                                                                         | .841                                         |                                |
| It's fun to do things with _____                                                                       | .807                                         |                                |
| I like having ____ in my family                                                                        | .717                                         |                                |
| My relationship with ____ is better than my friends relationship with their brother/sister/s           | .580                                         |                                |
| I try to avoid being around ____ too much                                                              | .707                                         |                                |
| My relationship with ____ is worse than my friend's relationship with their brother and or sisters     | .689                                         |                                |
| I can't have a normal relationship with ____ no matter how hard I try                                  | .646                                         |                                |
| I think having a brother or sister with an intellectual disability makes my parents expect more of me  |                                              | .541                           |
| I have more responsibilities in my family than my friends do                                           |                                              | .680                           |
| If I didn't help out, my mum would have too much work taking care of _____                             |                                              | .667                           |
| If I didn't help out, my dad would have too much work taking care of _____                             |                                              | .555                           |
| Life in my family is really different from life in other families                                      |                                              | .716                           |
| People look at my family differently when they know about ____'s disability                            |                                              | .708                           |
| Things are harder in my family because of ____'s disability                                            |                                              | .773                           |
| My family misses out on opportunities that other families get to do such as going on holidays together |                                              | .783                           |

#### 5.6.4 Part 2

Two factors were extracted from the PCAs of Part 2 – Social Life with eigenvalues greater than 2. All 17 items had factor loadings greater than 0.5. The correlation matrix for the final factor analysis is located in Appendix G2. Item P2E1 loaded on both Factor 1 and 2, however loaded higher on the former. Factor 1 contained 12 items with factor loadings greater than 0.5. This factor had an eigenvalue of 5.17 and accounted for 35.60% of the variance. The items related to siblings' worry about what others think. Factor 2 contained five items with factor loadings greater than 0.5. This factor had an eigenvalue of 3.23 and accounted for 19.00% of the variance. The items related to siblings' perception of lack of time with others. Together, both factors accounted for 49.44% of the total variance. These factors were subsequently defined as Siblings' Worry About What Others Think (Factor 3) and Lack of Time With Others (Factor 4). As for Part 1 of the measure, the integrity of the subscales in Part 2 remained throughout the two PCAs with subscales collapsing to form two overall factors (Subscales B, D, E and F forming Factor 1 and subscale H forming Factor 2). Thus, again the PCAs supported the thematic analysis.

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .77 for Part 2 and Bartlett's Test of Sphericity was significant, which suggested that the correlation matrix generated was suitable for the analyses. Cronbach's alpha coefficients revealed that Part 2 of the measure had high internal consistency (Part 2 Total = .85) along with high-moderate internal consistency for each

of the respective factors (Factor 1 = .87, Factor 2 = .76). The factor loadings of each item are reported in Table 5.4.

#### 5.6.5 Test-Retest Reliability

Test-retest statistics were calculated from data collected from the 34 participants returning a second completed questionnaire. Pearson's correlations conducted for the 4 subscale totals, at Time 1 and Time 2 (approximately 6 weeks later) were .79, .88, .78 and .89 for the *Positive Influence of Disability*, *Family Differences*, *Worry About What Others Think* and *Lack of Time With Others* subscales respectively. This indicates that participant's scores on the measure have high reliability across a 6-week period.

### **5.7 The Final PED Measure**

The final PED measure consisted of 40 items with four subscales (see Appendix J1). The expert panel assessed the face and content validity of the final Perceived Effect of Disabilities measure. A consensus was obtained that the items contained in the final draft were clear and representative of the relevant impacts of disability on siblings.

Table 5.4

*Factor Loadings of Items in Part 2*

| Item                                                                                        | Factor Loadings                           |                                      |
|---------------------------------------------------------------------------------------------|-------------------------------------------|--------------------------------------|
|                                                                                             | Factor 1<br>Worry About What Others Think | Factor 2<br>Lack of Time with Others |
| I'd rather people didn't know I had a brother/sister with a developmental disability        | .740                                      |                                      |
| I haven't told my teachers about ____ because I'd rather they didn't know                   | .652                                      |                                      |
| I am too embarrassed to tell my friends about ____'s disability                             | .598                                      |                                      |
| I make up stories about ____ because I'm too embarrassed to tell the truth                  | .605                                      |                                      |
| I think some of my friends feel funny around ____                                           | .569                                      |                                      |
| I think some of my friends feel uncomfortable about ____'s disability                       | .669                                      |                                      |
| Some of my friends act weird around _____                                                   | .623                                      |                                      |
| People feel too uncomfortable to talk about ____ with me                                    | .547                                      |                                      |
| Others try to avoid talking about ____ around me so they don't hurt my feelings             | .612                                      |                                      |
| I'm embarrassed about ____'s behaviour when we are in public together                       | .784                                      |                                      |
| I wish I could just disappear when ____ does embarrassing things                            | .699                                      |                                      |
| I pretend I don't know ____ when he/she does embarrassing things                            | .693                                      |                                      |
| I wish I didn't have to look after ____ so much                                             |                                           | .610                                 |
| I don't have much time to spend with friends after school because I have to look after ____ |                                           | .752                                 |
| I feel lonely and isolated from others                                                      |                                           | .728                                 |
| I feel angry that I have less chance to go on outings because of ____'s needs               |                                           | .656                                 |
| I wish I could have more fun with my friends                                                |                                           | .766                                 |

Table 5.5 presents the subscale titles and psychometric properties of each subscale. The means and standard deviations of each of the subscales are presented in Table 5.6. While figures are presented for each subscale, their respective part and for the total scale, at this stage, interpretations should be made at the part and subscale level only, until there has been further validation of the scale.

Table 5.5

*Subscales of the Final Perceived Effect of Disability Measure*

|        |               | Title                            | Number of Items | Total Potential Subscale Range <sup>8</sup> | Cronbach's $\alpha$ | Test-rest reliability |
|--------|---------------|----------------------------------|-----------------|---------------------------------------------|---------------------|-----------------------|
| Part 1 | Subscale 1    | Positive Influence of Disability | 15              | 0-45                                        | .91                 | .79                   |
|        | Subscale 2    | Family Differences               | 8               | 0-24                                        | .84                 | .88                   |
|        | Total         | Family Life                      | 23              | 0-71 <sup>9</sup>                           | .87                 | .84                   |
| Part 2 | Subscale 3    | Worry About What Others Think    | 12              | 0-36                                        | .87                 | .78                   |
|        | Subscale 4    | Lack of Time with Others         | 5               | 0-15                                        | .76                 | .89                   |
|        | Total         | Social Life                      | 17              | 0-51                                        | .85                 | .84                   |
|        | Total Measure |                                  | 40              | 0-105                                       | .84                 | .87                   |

<sup>8</sup> See Appendix J1 for scoring instructions

<sup>9</sup> *Positive Influence of Disability* scores are reverse coded when combined with scores across other subscales to produce Part 1 or total scores.

Table 5.6

*Sample Means, Standard Deviations and Ranges for Subscales<sup>10</sup>*

|                    | Positive Influence of Disability | Family Differences | Worry About What Others Think | Lack of Time with Others | Part 1 | Part 2 | Total |
|--------------------|----------------------------------|--------------------|-------------------------------|--------------------------|--------|--------|-------|
| Mean               | 29.20                            | 11.16              | 9.82                          | 3.72                     | 40.35  | 13.54  | 53.89 |
| Standard Deviation | 10.02                            | 5.86               | 7.34                          | 3.44                     | 11.79  | 8.90   | 14.94 |
| Range              | 2-45                             | 0-24               | 0-31                          | 0-14                     | 9-63   | 0-38   | 24-85 |

**5.8 Summary**

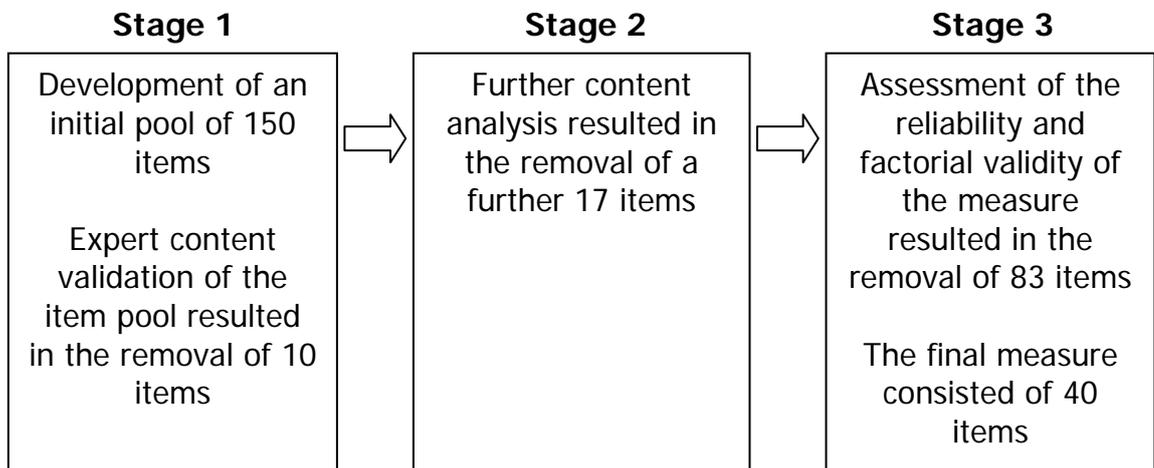
This chapter presented the final refinement of the PED measure. Further item reduction was achieved through assessment of the internal consistency, and factor analyses. The 40-item PED measure included four subscales: *Positive Influence of Disability*, *Family Differences*, *Worry About What Others Think* and *Lack of Time With Others*. The measure exhibited high content and face validity as well as demonstrating high internal consistency and test-retest reliability over a 6-week period.

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<sup>10</sup> See Appendix J1 for scoring instructions

### Chapter 6: Discussion of Study 1

The main aim of Study 1 was to develop a reliable and valid instrument that would measure the effect of disability on the lives of teenage siblings, as perceived by the siblings themselves. A review of the available literature indicates that the Perceived Effect of Disability measure is the first of its kind to be based on both quantitative and qualitative data from siblings themselves. It is also the only self-report measure for siblings' that has had psychometric properties such as reliability and factorial validity determined. While past research provided the initial item pool, and areas of interest, the combination of both quantitative and qualitative data, was used to assess the validity of the items and to refine the final measurement. The three stages of the measure's development are summarised in Figure 6.1:



*Figure 6.1* The three stages comprising Study 1.

The final Perceived Effect of Disability measure included 40 items assessing two major areas of impact for siblings, the effect on family life and the effect on social life. The scale demonstrates high internal consistency and test-retest reliability and an exploratory factor analysis revealed four underlying factors that are theoretically relevant. The final measure included four subscales covering the four underlying factors. This chapter will explore the results of Study 1, and compare them that of previous literature and previous measures (the very few that are available from the literature review). Next, the study limitations and strengths will be discussed along with the potential uses of the measure. Last, the implications of this research for practice and further research will be presented.

### **6.1 Factorial Validity**

The construct validity of this measure is evident from the results of the factor analyses, which demonstrate each item's loading on its corresponding factor (Comrey, 1988). Factor 1 emerged as the strongest factor in Part 1 of the measure, accounting for 31.2% of variance. This factor merged two subscales that were present in the early version of the measure - representing siblings' ability to recognise good things about their family in general, as well as the good things about their sibling with a disability and the relationship they have with their sibling. Overall, this final subscale represents the positive influences the sibling has gained from having a brother or sister with a disability, with higher scores indicating a more

positive influence and lower scores indicating a lack of perceived positive influence. Past research has identified a number of areas where siblings have been positively influenced by having a brother or sister with a disability (e.g., Jacobs, 1969; McHale et al., 1986; Miller, 1974; Wilson et al., 1989), and siblings themselves identified this as important through all stages of the present study.

Past research has indicated that many siblings feel that their family life is different from others (e.g., Nesa, 1999). Many feel they are restricted in the activities that they can do (Kirkman, 1985). In this study siblings themselves identified differences between their own family and others. The second subscale incorporated a number of subscales from the earlier version – representing siblings' perception of greater responsibilities than others, missing out on opportunities that others their age may have, and general perceptions that their family is different, to form the *Family Differences* subscale. Higher scores on this subscale indicate that siblings feel very different to others, whilst lower scores indicate that they view fewer differences between themselves and others. These two subscales formed Part 1 of the measure reflecting the – “Effect of Disability on Family Life”.

The third subscale measuring *Worry About What Others Think* was the strongest factor in Part 2 of the measure, accounting for 35.6% of variance. Embarrassment has been reported by many in the literature (e.g., Gath, 1973; Woodburn, 1973), along with a concern over the reactions of their

peers when explaining their sibling's disability (Nesa, 1999). The issues of embarrassment and explaining their brother or sister's disability to others formed a coherent factor that represented concern over what other's think about them, their sibling and their sibling's disability. Lower scores indicated less concern about what others think.

Due to the extra care needs of a child with an intellectual disability, past research has found there may be a restriction in the amount of time siblings spend with others their age (e.g., Crnic & Leconte, 1986). Siblings often have extra responsibilities around the home and participate in more care taking than others their age (Shere, 1956; Wilson et al., 1989). The fourth subscale *Lack of Time With Others* represents the perception that siblings have less time to do things that others their age do, with higher scores indicating greater concern in this area and lower scores indicating few difficulties. Thus, the overall factor structure of the final measure fits well with past literature.

There have been very few measures developed to specifically assess the effect of disability on siblings. Furthermore, the measures have not been developed using rigorous methodologies nor have extensive psychometric properties been reported for existing measures. Thus it is difficult to compare the present measure to past measures. The factors emerging from the present study were not conceptually related to the subscales developed in the *Sibling Problems Questionnaire* (SPQ) (McHale et al., 1986). However

items on the Family Differences subscale covered similar issues to those on the hyperresponsibility scale of the SPQ. Similarly, items on the Worry About What Others Think subscale were similar to the Positive Reactions By Peers subscale of the SPQ. Items on the Worry About What Others Think subscale were similar questions on the Impact on Peer Relationships subscale in the *Sibling Statement Scale* (Wilson et al., 1989). Items in the Positive Influence of Disability subscale appear related to the Impact on Personal Development/ Positive Impact and Impact on Feelings About Self and Handicapped Child subscales of the *Sibling Impact Questionnaire* (reported in Eisenberg et al.'s 1998 study). Items in the Worry About What Others Think subscale were related to those in the embarrassment subscale of the *Schaffer Sibling Behaviour Rating Scale* adapted by McHale et al. (1986). The factors did not correspond with any domains on the *Sibling Need and Involvement Profile (SNIP)* (Fish, 1994) or those of the measures published in Siegel and Silverstein's (1994) book.

Past measures have not been developed through rigorous methodologies, and the psychometric properties have only been reported for three of the measures (*Sibling Impact Questionnaire* reported in Eisenberg et al.'s 1998 study; *Sibling Problems Questionnaire* by McHale et al, 1986; *Schaffer Sibling Behaviour Rating Scale* developed by Schaeffer & Edgerton, 1979, cited by McHale et al. & Wilson et al., 1992). For example, only the internal consistencies of the *Sibling Problems Questionnaire* (McHale, et al.) and *Sibling Impact Questionnaire* reported in Eisenberg, et al.'s study) have been

reported. Furthermore, the factor structure of only one measure (*Schaffer Sibling Behaviour Rating Scale* developed by Schaeffer & Edgerton) has been reported. Thus, past measures have failed to demonstrate adequate reliability and validity.

## 6.2 Reliability and Validity

It was expected that the scale developed would have content and face validity, internal consistency, and reliability over time. The measure exhibited high internal consistency across each subscale and part as well as over the total scale (Cronbach's  $\alpha$  Factor 1 = .91, Factor 2 = .84, Factor 3 = .87, Factor 4 = .76, Part 1 = .87, Part 2 = .85, Total scale = .84). The measure also exhibited reliability over a 6-week period (Pearson's correlation coefficients Factor 1 = .79, Factor 2 = .88, Factor 3 = .78, Factor 4 = .89, Part 1 = .84, Part 2 = .84, Total scale = .87). None of the other sibling measures used in previous literature reported such reliability data. The measure exhibits extensive content validity due to the methodology employed to develop the measure. All items were based on recent research literature, as well as the existing measures. The target population was consulted in all stages of its development and they provided extensive validation of the range and importance of the issues covered. Thus, the items have face validity – siblings have reviewed all items that ended up in the final version for relevance and clarity. Items that were not clear were dropped or re-written. Siblings of children with intellectual disability believed

that the items in this measure would accurately assess their perceptions about the impact of their brother or sister's disability on their lives. Thus, the results of this study represent excellent reliability and validity in terms of test construction literature.

### **6.3 Limitations of the Present Research**

The major limitation of the present research is participant numbers. Most researchers agree that a minimum of 100 participants are required for a factor analyses. Kline (1986) recommends a minimum of 200 subjects in order to have a low standard error rate when conducting reliability studies on tests. However, due to the number of stages in Study 1 and the limited number of participants in Western Australia, these sample sizes were not available. Attempts to access participants from other states in Australia were not successful for a variety of reasons. Furthermore, in order to increase the participant to item ratio, an internal consistency analysis was conducted prior to the exploratory factor analysis rather than the typical procedure of conducting it after the factor analysis.

Most agree that the development of a new measure should include both an exploratory and confirmatory factor analysis to ensure that the items load on their respective factors. Confirmatory analyses typically use an alternate sample of participants, or the original set is split in two to accommodate both analyses. Given the small sample size of Stage 3 of Study 1 and the

difficulty accessing more participants, these options were not within the scope of the present study.

The education levels of parents/caregivers of participants in this study was higher than that of the national average reported by the Australian Bureau of Statistics (2002) which states that 57% of Australians have an educational level above secondary high school, while 18% have university education.

The marriage rates of participants' parents in this study varied greatly from the national average reported by Australian Bureau of Statistics (2003), with those families participating reporting much lower rates of divorce than the average. Hence, the current sample may be a more educated and stable group compared to the general population.

It is interesting to note that the majority of parents who took their children to the focus group sessions did not wish to watch the film that was offered while they were waiting. Many parents had seen the film previously and preferred to exchange information with each other. Thus it may be that families who participated were more likely to access resources, a factor which has been associated with benefits to overall family functioning, in previous research (e.g., McCubbin & Patterson, 1983).

#### 6.4 Strengths of the Study

While participant numbers across all stages of the present research were lower than ideal, overall a large percentage of eligible participants were accessed in this research. From families' responses across Study 1<sup>11</sup>, it was determined that 30.6% of the total number of families contacted had a sibling eligible to participate. Given that data from 144 eligible participants were used in data analysis for Study 1, this represents 58.5% of the population contacted.

Overall, there was a positive response from families, with many responding to invitations to participate in the project even if they did not have children who were in the age-range. Some families completed the questionnaire even if their child wasn't in the age-range, as they believed that it was helpful for their child. One mother wrote on her child's questionnaire- "I hope you will consider including my daughter's questionnaire even though she isn't in the age-range. She has had a hard time with her brother and this is a good opportunity to get her feelings down and opinions across". This indicates the strong need for services/resources for siblings of children with an intellectual disability in Western Australia. The development of this measure has increased awareness of sibling needs in Western Australia, through the various advertisements aired on various radio stations and articles published through local papers.

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<sup>11</sup> These responses include those responding by sending back the participation slips, contacting the researcher or through the follow-up phone calls made in Study 1 of all those eligible to participate. It is acknowledged that this rate may be an underestimate of the true figure, given that families may not have responded due to the research not being relevant to them, although it was requested that they respond regardless.

## **6.5 Implications**

This new measure can be used to evaluate the sibling needs and to direct services. As the majority of sibling research has relied on parental reports or measures used for alternative populations, this measure should increase the quality and accuracy of research exploring the effects of disability on siblings. Use of the measure by researchers and service providers may then provide evidence for the need of more services for siblings in Australia. In addition, the measure can also be used as a tool to assess the effectiveness of interventions for siblings.

## **6.6 Future Directions**

Future research should test the PED measure on a larger sample of participants (>200 participants) in order to ensure the generalisability of the results and to allow sufficient participant numbers for further analyses. Confirmatory factor analyses should then be conducted on the data to provide additional support for the factor structure found in the present study. If the factor structure is confirmed, the use of the total scale scores along with the scores for the separate parts of the measure (the effect of disability on sibling's family life and the effect of disability on sibling's social life) will increase the utility of the measure.

Future research with a larger sample should collect data from an equal number of younger siblings and older siblings and compare the effects on both to determine developmental considerations that are relevant to families. Future research could also determine the measure's suitability for younger siblings (i.e. under 12 years of age), as well as siblings of children with other special needs (such as physical disabilities, chronic illnesses). If these analyses provide evidence for the reliability of the measure with these other groups, the utility of the measure would be extended.

While this study has demonstrated the content and face validity, internal consistency, and reliability of the PED measure over time, future studies should further investigate the construct validity of the measure. The convergent evidence for the validity of the measure should be explored by comparing the PED measure to other measures of similar constructs. The discriminant validity of the measure should also be examined. This type of validity demonstrates that the measure is not correlated highly with measures that purport to measure different constructs (Kaplan & Saccuzzo, 1997).

## **6.7 Conclusions**

It is evident that there are varied effects on the family and social lives of siblings of children with an intellectual disability. Through quantitative and qualitative evaluation, the present study constructed an item pool, which

developed into a reliable and valid measure of the Perceived Effect of Disability on adolescent siblings of children with an intellectual disability. Without such a measure, future researchers will continue to fall into the trap of relying on parental reports or measures that have not been validated, both of which may compromise their overall results. This research will advance research into sibling adjustment by ensuring that the subjective thoughts and feelings of siblings are assessed, rather than relying on second hand reports from parents or other informants.

## *Chapter 7: Services and Supports for Siblings*

### **7.1 Introduction**

The aim of Study 2 was to develop and pilot an intervention for teenage (12-17 yrs) siblings of children with an intellectual disability and to use the PED measure constructed in Study 1 as an outcome variable. As a consequence of the limited research that has explored the effects of disability on siblings, there have been few services available for siblings in our community. Of those services, even fewer have been developed for teenagers. The teenage years are a time of transition and identity formation and can be stressful and confusing for many (Adams, Gullotta, & Markstrom-Adams, 1994). Hence, if siblings' needs have not been recognised or met, by the time they are teenagers their relationship with their sibling with a disability may be endangered. Services for this group are important.

The information on teenage siblings' perceptions of the effect of living with a brother or sister with a disability from data collected in Study 1 provided the basis for the development of a 6-week intervention program. The intervention aimed to assist the positive adjustment of teenage siblings of children with an intellectual disability. Many factors have been found to affect the adjustment of siblings of children with disabilities in the family. One model that aims to predict family functioning is the Double ABCX model (McCubbin & Patterson, 1983). This model has been most successful when applied to families of children with an illness/disability (e.g., Orr et al., 1991).

Research on this model will be reviewed in this chapter to provide the context for the development of the intervention program. The results of research evaluating the effects of interventions developed for siblings are reviewed and then methodological considerations are discussed. Next a discussion of the common components of these interventions is presented along with a list of additional needs. The chapter concludes with the rationale for Study 2, plus the research hypotheses.

## **7.2 Double ABCX Model**

The Double ABCX model was developed to explain families' post-crisis adaptation (Patterson, 1993). Hill's (1949) original ABCX model suggests that characteristics of the stressor (A) interact with the family's resources and support networks (B), along with the family's perception of the stressor (C) to influence the impact of a crisis (X). This model predicts positive adjustments if the family's resources and support networks are high, along with a positive perception of the stressor.

McCubbin and Patterson (1983) built on Hill's (1949) original ABCX theory of family stress by including post-crisis adaptation. Their Double ABCX model includes the build-up of other stresses related to the family making adaptation more difficult (aA). Thus, it accounts for stressors experienced over time. This version also includes an interaction between the family's perceptions of these stressors, their resources and their ability to cope.

Lazarus and Folkman (1984) argue that if one's resources are adequate for the stressor, one is able to adapt even when the demands are high.

The Double ABCX model takes into account both cognitive as well as behavioural coping factors (Patterson, 1993). This has implications for interventions aimed at increasing family adaptation to a child with an intellectual disability. It suggests that interventions that aim to positively influence the adjustment of family members of children with an intellectual disability should target the family's resources, such as social supports, along with family member's perceptions of the stressor.

The Double ABCX model has been successfully applied to families of children with an illness/disability (McCubbin & Patterson, 1983; Orr, Cameron, & Day, 1991). However, it is important to note that most studies exploring this model with families who have a child with a disability have explored the empirical utility of the model, rather than compared the model with other models in order to determine the most successful model for families who have a child with a disability.

Wikler (1986) has conducted a review on family stress theory with families of children with an intellectual disability and argues that evidence supports the components of the model. Orr et al. (1991) evaluated the Double ABCX model with 86 families of children with an intellectual disability. They found support for the model, however suggest an ACBX model rather than the

ABCX model. Thus, family member's interpretation of the meaning of their situation may influence effectiveness of support and resources (Orr et al.). Bristol (1987) has also found evidence to support the Double ABCX model with mothers of children with autism and communication disorders. Similarly, Shin and Crittenden (2003) evaluated the model with 40 Korean and 38 American mothers of children with an intellectual disability. The researchers found partial support for the overall model, however found that the path models differed between the two groups in that stress was more related to individual variables for American mothers while it was more related to social variables for Korean mothers. Furthermore, Frey et al. (1989) found evidence that problem-focused coping styles were related to lower psychological distress of parents of children with an intellectual disability. Hence, the present study aimed to develop an intervention targeting siblings' resources, particularly support networks and coping skills, whilst also focusing on siblings' current perceptions of their situation.

### **7.3 Sibling Interventions and Services**

The majority of interventions for siblings of children with disabilities described in the literature involve group-based interventions (e.g., Evans, Jones, & Mansell, 2001; Lobato, 1985; McLinden, Miller, & Deprey, 1991). The groups vary greatly in terms of participant numbers, inclusion criteria and intervention content. Most interventions focus on children under 12

years of age. This section explores the common components, successful methods and main problems of past studies.

One of the most popular programs available for siblings is *Sibshops*. Meyer, Vadasky, and Fewell (1985) developed Sibshops, as a peer support and educational program for 8-13 year old siblings of children with special needs. The program is designed to be run in a group setting, however Sibshops can be run in a variety of ways, including workshops, meetings or in discussion panels. The peer support and education is delivered in an informal environment with a strong recreational emphasis. The authors list five main goals: the opportunity for siblings to meet others, to discuss their joys and concerns, to learn how others deal with challenging situations, to learn more about their brother or sister's condition and to allow parents the opportunity to learn common concerns of siblings. They include sibling and parent discussion activities, information and recreational activities. The sibshops can be run as frequently as required (for example, once a month/year etc.). This program appears to be the most well-known program for siblings, which has been reported to be run all over the world including – the United States of America, Canada, England, Ireland, Croatia, Japan, New Zealand, Iceland, Mexico, Argentina, Guatemala (<http://www.thearc.org/siblingsupport/sibshops-about>) and in Australia ([http://www.carpentaria.org.au/newletters/june02\\_4.htm](http://www.carpentaria.org.au/newletters/june02_4.htm)). Despite this, only one published research paper on the effectiveness of the program could be found on PsycINFO in 2004.

Schongalla (2003) conducted research with 31 siblings between the ages of 7 and 13 years to determine if the five goals of the Sibshops were being met. Feedback forms were given to siblings and parents. Schongalla found that the first three of the five goals of the Sibshops were being met, though the goals of providing siblings with the opportunity to learn problem-solving skills and learning more about disabilities were not being met. However, no psychometrically solid measures were used in this study. Apart from this study, only anecdotal evidence pertaining to the enjoyment of the sibshops has been reported.

Lobato (1985) developed an intervention for young siblings (aged 3 to 7 years) of children with disabilities. The aim of the intervention was to: improve understanding of the developmental disabilities; to increase children's recognition of their strengths, and the strengths of their disabled brother or sister, and of other family members; and to improve their skills in constructively expressing negative emotions associated with their unique situation. There were six children in the study - with five of these being older siblings. The children attended two groups, one for the three girls and one for the boys.

The groups ran over a six-week period - with siblings meeting once a week for 90 minutes. Training procedures such as modelling, coaching and role-play were used along with art materials, puppets, human-like dolls, and children's books on disabilities. Lobato (1985) used a role-play assessment

as the primary means of evaluating the impact of the workshops on the siblings' functioning, along with a 30-minute momentary time sample of sibling interaction with their brother or sister with a disability conducted by the parents.

Five of the six siblings displayed increased levels of positive verbalisations about their families after the 6-week intervention whilst four of these five children also displayed a decrease in the use of negative verbalisations about their families (Lobato, 1985). Lobato also documented an increase in "positive self-reference statements" and a decrease of "negative self-referents" for four of the participants post-intervention. Lobato concluded that the overall goals of the intervention were attained. However, she also noted the limited generalisability of the results, as the role-play data could not be externally validated and no other outcome measures were used.

McLinden et al. (1991) evaluated the effects of a 6-week support group for six school-aged siblings of children with special needs ( $M = 9.17$  yrs) compared to five children who couldn't attend the groups ( $M = 10.6$  yrs). The group sessions were run for one hour per week and were adapted from Lobato's (1985) program. To ensure the program was appropriate for the older age group, the researchers included activities from other programs such as Meyer et al.'s (1985) program. For example, an activity called "Dear Aunt Blabby" (Meyer et al.) was included to discuss difficulties that siblings face and explore options in overcoming them. Role-play was used to present

situations siblings may encounter with their peers. Homework assignments were also incorporated to strengthen the concepts covered in the groups. The overall aims of the intervention were to allow siblings to express their feelings, to provide peer support and coping strategies.

The Child Behaviour Checklist (Achenbach & Edelbrock, 1983) and Piers-Harris Children's Self-Concept scale (Piers & Harris, 1969) and measures of social support were used along with parent interviews to measure changes in sibling's adjustment across time. Children who participated in the support group perceived their level of social support, as measured by the Who Helps Me Scale (McLinden, 1987 as cited by McLinden et al., 1991), to be higher than those who did not receive the intervention. In general, parents of experimental group children found that behaviour towards their sibling with special needs improved post-intervention. However, the researchers found no significant differences between the two groups in terms of the level of behaviour problems, changes in self-concept, or attitude towards and knowledge of the child with a disability. This study had several limitations such as low participant numbers (6 children in the intervention group and 5 in the control group), resulting in lack of power. Furthermore there was non-random assignment of participants to the two groups – the assignment of participants to groups was based solely on their ability to attend the intervention groups, and thus, participants were not matched on important variables such as age and gender. The researchers also note that the way participants viewed their brother or sister's disability was related to their age

and thus the effectiveness of the intervention may also be depend on the participant's age. Lastly, the study lacks generalisability due to an over-representation of females (8 females, 3 males).

Phillips (1999) evaluated a community-based intervention developed for economically disadvantaged African American siblings of children with intellectual disabilities. One hundred and eighty children between the ages of nine and 12 years of age participated in the study with participants randomised to either an intervention group or a control group. The intervention was a 15-week program incorporating group recreational activities, discussion about developmental disabilities, discussion of any concerns that siblings may have, and assistance with homework. Phillips stated that the groups aimed to decrease stress by providing information and social support. Phillips reported that the intervention group had decreased depression (as measured by the Children's Depression Inventory, Kovacs, 1985) and anxiety symptoms (as measured by the Children's Manifest Anxiety Scale-Revised, Reynolds & Richmond, 1985) and increased self-esteem (as measured by the Self-Esteem Questionnaire, DuBois, Felner, Brand, Phillips, & Lease, 1996), whilst the control group showed no improvement at post-intervention. Furthermore, the intervention group reported less sibling-related stress (as measured by the Daily Hassles Questionnaire, Rowlison, & Felner, 1988) and increased social support (as measured by the Social Support Scale-Revised, DuBois et al., 1996; Procidino & Heller, 1983) after the intervention. These results are promising.

However, no significant intervention effect was found for family functioning (as measured by the Family Environment Scale, Moos & Moos, 1986) or sibling relationship (as measured by the Sibling Relationship Questionnaire, Buhrmester & Furman, 1990; Furman & Buhrmester, 1985). As the researcher points out, because the intervention comprised three components, it is very difficult to tease out the effects of each component. Nevertheless, this is a particularly well - designed study, utilising psychometrically sound measures.

In 1988, staff from a special education school in the UK began running support groups for young siblings of children with severe learning disabilities (Flynn & Meakin, 1989). The group sessions were run after school and involved recreational activities, which served to give a balance between amusement and dealing with the issues that come up for siblings. Social skills training was incorporated into the group sessions based on a program developed by Flynn (1988). The training included indirect learning through trust and cooperative games, and practice solving problems such as how to deal with teasing. The intervention also included use of children's literature such as *Getting Through to Your Handicapped Child* (Newson & Hipgrave, 1982), plays portraying an aspect of their family lives; special colouring books which helped children understand what it's like for children who have a disability; a modified part of an Open University Course looking at *Mental Handicap Patterns for Living*; and, maintaining contact with other group members and facilitators through a newsletter.

The researchers argued that such groups were welcomed by parents and siblings and were aimed at improving family relationships (Flynn & Meakin, 1989). Whilst the design of the groups was novel, the researchers did not systematically evaluate the effectiveness of the support groups through incorporating a control group or collecting pre and post-test data on the intervention outcomes. Thus, it is difficult to draw any conclusions about the efficacy of the program.

Evans et al. (2001) evaluated a support program for brothers and sisters of children with learning disabilities and challenging behaviours. This program was aimed at enhancing siblings' relationship, understanding of learning disabilities, coping skills, and providing an outlet for expressing feelings in a safe and supportive environment. A pilot group was initially run with 10 children (aged 6-12 years) and then two subsequent programs were implemented with nine children in each group (aged 7-12 years). The group sessions ran for three full days during the school holidays and then weekly for six weeks with a final fun day at a local theme park. The sessions were structured with a problem-solving focus (Evans et al.). Siblings created puppets or masks to represent how they viewed their brother or sister with a disability, they were taught games that they could play with their sibling, as well as relaxation skills. The authors reported that parents felt relationships in the family had improved since the child had started participating in the groups. Family relation scores significantly increased at post-test, as did knowledge of disabilities and challenging behaviours. Siblings' self-esteem

scores also improved post-intervention. However, no comparison groups were used to ensure these changes were attributable to the intervention and not due to other influences such as history and maturation. Thus, no definite conclusions regarding the effectiveness of the program can be made.

The NCH Action For Children organisation, in partnership with the North Yorkshire Social Services, piloted a sibling support program with siblings of children with disabilities (Atkinson & Crawforth, 1995). Thirty siblings, both younger and older teenage siblings, aged eight to 16 years, participated in a number of evening sessions (unfortunately the authors do not specify how many) followed by a residential weekend of fun. Although the authors did not conduct a rigorous evaluation of the program, they collected qualitative data from the siblings who participated. Based on this data, the authors stated that 97% of the siblings who participated believed that the group had helped them, particularly in learning that there are others in a similar situation to themselves. Seventy-three percent of the siblings indicated that they had made helpful or special friendships at the groups with many believing that they had gained valuable knowledge about their brother or sister's disability. Nearly 70% reported that it was useful to have an adult outside of the family to talk to.

Badger (1988) documented the experience of a program run for young siblings of children with physical disabilities. Eight children (3 boys and 5 girls) between the ages of 5½ to 7½ years attended the group sessions,

which ran weekly for two-hours over a seven-month period. The aims of the program were to: provide something for siblings which they could attend without their brother or sister which was fun for them and where they could do something that they might not otherwise be able to do; to provide information about their sibling's condition and share experiences with other siblings; and last, to provide an avenue for expression of feelings through such activities as acting, drawing, painting and talking. Unfortunately the authors did not formally evaluate the program. However, they reported that informal observations of the program indicated that the siblings enjoyed and benefited from the group.

A suggested format for a 6-week sibling support group has been published by Summers, Bridge and Summers (1991). The program appears to be motivated by a lack of materials to help service providers plan for sibling groups. The program suggested by Summers et al. aims to provide information and coping strategies to siblings and involves ice breakers, picture drawings, planting (a bean to symbolise growth and difference), sensory impairment activities, book reading, role-plays, videotapes, guest speakers, story sharing and a pizza party at the conclusion of the program. The program appears to have some evidence regarding its effectiveness with the authors referring to a paper they presented in 1989 at the Council for Exceptional Children. Summers et al. state that compared to a control group, siblings of children with disabilities who attended the groups became

less dominating over their brother or sister with a disability. However, no other information regarding the effectiveness of the program was reported. Support programs for siblings of children with chronic illness have been developed. Cunningham, Betsa and Gross (1981) ran group sessions with siblings of children in a paediatric oncology ward. Ten siblings aged between nine and 12 participated in a group for one and a half hours a week for five weeks, whilst their parents also met in another location at the hospital. The group sessions were run with siblings identified as having problems. Interviews conducted with parents one year after the programs, found that the group sessions had ongoing positive effects on the participants, with children being able to verbalise their feelings about their sibling's illness and various matters relating to hospital issues. Parents also reported decreases in attention-seeking behaviours from the siblings. However, there were no psychometric measures used to assess changes in the outcome variables. Apart from the parent interviews, only informal observations were used to establish a record of positive changes to siblings.

Similarly, Houtzager, Grootenhuis and Last (2001) conducted an evaluation of support groups for siblings of children with cancer. Participants included 24 children aged between seven and 18 who attended five sessions. The main aim of this study was to evaluate the effect of group participation on the anxiety levels of siblings. Post-test data indicated that siblings' level of anxiety had declined from pre-intervention, suggesting that participation in the support program reduced anxiety levels. However, as the authors

acknowledge, this study was limited by not having a control group, it had a small number of participants, incorporated siblings from a large age-range and only one outcome measure was used.

Heiney, Goon-Johnson, Ettinger and Ettinger (1990) reported on a program run for siblings of paediatric oncology patients. The program aimed to relieve stress and enhance coping. There were 14 siblings aged between nine and 15 years in the group sessions which ran over seven one-hour sessions. The effects of the program were assessed through a quasi-experimental design with a non-equivalent control group used at pre and post-test. The only measures used to assess the effectiveness of the program were the peer relations and family subscales of the Social Adjustment Scale (Weissman & Bothwell, 1976). However, there are no psychometric properties available for these subscales, with only the total scale reliability available. A measure of evaluation was developed by one of the researchers to evaluate the group sessions and the therapeutic benefits, and while the inter-rater reliability of this measure is reported, no other data regarding the psychometric properties of the measure are discussed.

Furthermore, the researchers failed to conduct adequate statistical analyses on the data with only independent group t-tests conducted on pre and post-data for each group. The researchers report that there were no significant differences found between the groups however they do not specify if this was the case for both pre and post-test data. From the qualitative data the

authors reported that siblings overall enjoyed the program, experienced a decrease in their sense of isolation, they were able to off-load negative feelings, and learn from one another. Furthermore, Heiney et al. state that the descriptive data suggested a need for ongoing follow-up with siblings to help them manage the stresses emerging from the impact of the diagnosis and treatment on the family. However, it is difficult to draw any meaningful interpretations from this study due to the limited analyses and resulting discussion from the researchers.

Findings from previous research indicate that siblings programs are enjoyed by participants (e.g., Badger, 1988). However many have lacked appropriate outcome measures (e.g., Cunningham et al., 1981; Flynn & Meakin, 1989) and have had difficulty obtaining sufficient sample sizes to achieve adequate power (e.g., Lobato, 1985). Nevertheless, the studies that have been methodologically sound (e.g., Phillips, 1999), have found evidence that siblings benefit from attending such programs. Phillips found that siblings receiving a 15-week intervention had many positive outcomes such as lower depression and anxiety symptoms and higher self-esteem compared to a control group.

As families who have a child with a disability often have limited time, some organisations prefer to conduct sibling workshops over the weekend or school holidays. Robinson (1980) conducted a 3-day workshop for siblings (aged 7 to 17 years) of children with a disability. The aim of the workshop

was to learn about their feelings and to see what their brother or sister does during the day. The group was split into two with younger siblings seven to 12 years being in one group and older adolescents 13 to 17 years forming another group. Each group met the professionals working with their brothers and sisters, such as Occupational Therapists and Speech Therapists. Art activities and disability simulations were also undertaken. A carnival was organised for the last day and teenage siblings held rap sessions and visited a group home for people with disabilities. The group home experience and rap sessions led to discussions about issues such as sterilisation and genetic counselling (Robinson). Robinson described how the workshop sessions for teens “were explorations of facts and feelings about themselves, their families, their handicapped brothers and sisters, and that important reality - the public” (p. 13). The teenagers were also invited to attend a talk with their parents about the causes of physical disabilities. Robinson argued that bringing siblings together was an overall beneficial experience as it allowed them to share information and experiences. No objective outcomes were outlined prior to the workshop sessions and there was no effectiveness study conducted. This appears to be the case for many disability organisations that have limited staff with expertise in research.

Strohm (2001) reported on a workshop run by the South Australian Sibling Project for young siblings (aged between 8 and 11 years). The workshop was aimed at allowing the siblings to share their experiences, their feelings and also discuss ways of coping, and to have fun. Reports from the siblings

after the workshop indicated that they had learnt coping skills, that they were not alone in their situation, and insight into other's feelings (Strohm). However there were no outcome measures used. A different sibling one-day workshop has also been reported by Byrnes and Love (1983). They describe sibling workshops sponsored by the South Central Regional Centre for Services to Deaf-Blind Children as "evolved from an attitudinal change in viewing the handicapped child within the context of his/her family", (Byrnes & Love, p. 4). The authors go on to explain that the expression of feelings is not targeted directly though this may occur spontaneously through the activities arranged. The focus of these workshops was sharing age-appropriate information and participating in recreational activities with the overall goal being to encourage peer interaction outside the family unit (Byrnes & Love). This approach was published in a disability organisation newsletter with no reports on the outcomes of the program for those attending.

The above review of past studies suggests that obtaining sufficient participant numbers, specifying outcomes from the outset, and gathering evidence of the effectiveness of the program through established outcome measures are important factors to consider when developing a sibling program. The implementation issues related to sibling programs will now be covered.

## 7.4 Implementation Issues

It is important that any intervention developed be based on the needs of the individuals targeted, in this case siblings, as well based on the research into the impact of disability on families and theories of family stress and adaptation. Dyson (1998) conducted a study exploring what siblings learn in a support program and what they most enjoy about the program. If we know what siblings enjoy, we can use this to increase participation rates in sibling programs and increase consumer satisfaction. In Dyson's study school-aged siblings between the ages of 7.5 and 12 years were invited to participate in six 2-hour workshops consisting of arts and craft activities, learning about disabilities, discussions involving sibling experiences and recreational/social activities. Siblings were asked to complete questionnaires about what they believed they had learnt from the support group, their preferred activities, and meeting times.

Aspects of the program rated as the *most liked* activities for more than a third of siblings in Dyson's (1998) groups was learning about their brother or sister's disability and the best way to interact with them. Siblings were not asked about the least enjoyable aspects of the program, however when asked about what other things they would like the groups to include, many siblings suggested learning more about their brother or sister who had a disability. Furthermore, many also expressed a wish to meet a person who had grown up with a brother or sister with a disability and some participants wished that they could learn more about other special needs. Practicalities

of the meetings were also explored. Over three-quarters of the participants indicated that they preferred to meet weekly or bi-weekly. Saturdays were also identified as the preferred time for meeting. This information is helpful in planning the structure of sibling programs.

Many argue that providing age-appropriate information to siblings of children with special needs serves an important role in helping to alleviate worry (e.g., Bendor, 1990; Gibbs, 1993). Meyer and Vadasky (1997) go so far as to state that information is “the most basic need siblings experience” (p. 62). They suggest ways of minimising the concerns of siblings and maximising their opportunities by providing them with age-appropriate information: opportunities to meet other siblings in similar situations and encouraging good communication between family members. In addition, strategies for parents were suggested such as encouraging them to spend special time with siblings; reassuring their sibling by discussing plans for the future; and for parents to learn more about what it is like for siblings. Seligman and Darling (1997) suggest that siblings may require information about their brother or sister’s special needs due to parents’ unwillingness to discuss such issues.

Kate Strohm (South Australian Sibling Project, 2000) reports that there are four main strategies to enhance sibling adjustment. The first is providing information for siblings and including them in discussions regarding the child with special needs in the family. Next is allowing siblings permission to

express *all* of their feelings. It is also important to help siblings to understand that they too are special and valued. Last, is helping siblings to access social support from other siblings in similar situations, their friends, family (including grandparents etc.), teachers, doctor and other professionals.

Slade (1988) argues that role-plays can be a particularly useful way for exploring sibling's feelings. Slade suggests using a situation presented by one or more participants and asking one group member to role-play a family member. Another group member or the facilitator can role-play the child with a disability and a third member can play the sibling role. This is followed by a discussion and children swap roles to learn other ways they may solve problems. Role-play has been successfully included in past programs such as Sibshops (Meyer et al., 1985; Meyer & Vadasky, 1994) and those run by Evans et al. (2001) and Flynn and Meakin (1989).

### **7.5 Past Studies Involving Sibling Programs**

As evident from the published literature on sibling groups and workshops described above, the aims, objectives and overall evaluations of these interventions have varied greatly. There is a lack of empirical Australian evidence for sibling programs. Thus, it is helpful to draw from the common themes of past programs and include components that have proven successful in past.

This review of existing programs suggests a number of important content areas for future programs. From the program objectives reported in past research, a list of common content is presented in Table 7.1.

Table 7.1

*Objectives of Past Programs*

| Content                                                  |                                                                                                                                                                                                 |
|----------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Sharing information about own family                     | Summers et al. (1991), Houtzager et al. (2001)                                                                                                                                                  |
| Learning information about disability/illness            | Cunningham et al. (1981), Byrnes & Love (1983), Lobato (1985), Badger (1988), Atkinson & Crawforth (1990), Summers et al. (1991), Phillips (1999), Houtzager et al. (2001), Evans et al. (2001) |
| Understanding about what it's like to have special needs | Robinson (1980), Flynn & Meakin (1989), Summers et al. (1991)                                                                                                                                   |
| Recognition of differences                               | Summers et al. (1991)                                                                                                                                                                           |
| Recognition of individual and sibling strengths          | Lobato (1985)                                                                                                                                                                                   |
| Expression of feelings                                   | Lobato (1985), Badger (1988), McLinden et al. (1991), Houtzager et al. (2001), Strohm (2001)                                                                                                    |
| Coping strategies                                        | Flynn & Meakin (1989), Heiney et al. (1990), McLinden et al. (1991), Phillips (1999), Strohm (2001)                                                                                             |
| Social Skills                                            | Lobato (1985), Flynn & Meakin (1989)                                                                                                                                                            |

Previous literature suggests that sharing information about family (e.g., Houtzager et al., 2001), learning information about disability (e.g., Phillips, 1999), helping siblings understand what it's like to have special needs (e.g., Robinson, 1980), recognising differences (e.g., Summers et al., 1991) and strengths (e.g., Lobato, 1985), expression of feelings (e.g., Strohm, 2001), coping strategies (e.g., McLinden, et al., 1991) and social skills (e.g., Flynn & Meakin, 1989) need to be included in a comprehensive program for siblings. Hence, the development of the present program will draw from these common areas. The Double ABCX model (McCubbin & Patterson, 1983) fits nicely within these content areas. The model predicts positive adjustments if the family's resources and support networks are high (bB), along with a positive perception of the stressor (cC).

As Wikler (1986) points out, there are many different features of family resources such as: individual, marital, family, extended family, intimate friends, friends and neighbours, community groups, clubs and professionals and organisations. Thus, the social support network activities in the present program will focus on helping siblings identify varying types of resources available. Siblings will also be provided with a list of outside support networks, and discuss the barriers of accessing support. Relaxation strategies such as breathing exercises, progressive muscle relaxation and visualisations will also be included. These activities may all assist with influencing a sibling's perspective of their situation (cC). Thus, there is

strong empirical evidence for the Double ABCX model and theoretical support for the strategies included in the present intervention.

## **7.6 Services for Siblings**

The services for siblings of children with an intellectual disability, in Western Australia, are scarce. Currently, in Western Australia there are few sibling camps and meetings available for siblings. However, the majority only includes siblings below the age of 13 years and has an emphasis on respite and having fun. While these services play an important role in siblings' adjustment, there is no avenue for siblings to discuss what life is like for them in a safe and supportive environment.

Work is being done to provide more support for siblings, with many overseas organisations developing programs to support siblings. For example, Sibshops, (Meyer et al., 1985; Meyer & Vadasky, 1994) a peer support program originating from the US has been very popular. However Sibshops was not developed to produce therapeutic outcomes and hence the effects have not been properly evaluated.

While some researchers have been involved in the evaluation of interventions, other organisations have struggled to conduct any reliable evaluation of services provided. Of the research studies that have conducted evaluations of services for siblings, many have been plagued with

methodological problems, such as very small sample sizes and no follow-ups included. Nevertheless, the studies reviewed below suggest that the interventions provided benefits for siblings attending them.

### **7.7 Rationale and Aim of Stage 2**

A Family Systems perspective suggests that if we increase the resilience and consequently the adjustment of one member of the family, this will ultimately have a positive effect on the whole family (Patterson & Garwick, 1994). As it is recognised that the roles siblings play in their brother or sisters' health, happiness and community life are vital, Strohm from South Australian Sibling Project, (now Siblings Australia Inc.) (2000) argues that if sibling's feelings are validated and their needs met early in life, then they may be able to provide support for their brother or sister with special needs later in life. In general, the South Australian Sibling Project (2000, p. 3) advocates that sibling support can: improve the mental health of siblings; allow siblings to reach their full potential; be a sound investment to service providers; improve the quality of life of people with disabilities and; rebalance societal views.

The present study aimed to develop a program based on the Double ABCX model (McCubbin & Patterson, 1983) to increase siblings' resources particularly support networks; and increase positive views of their situation. The literature review indicates that while a number of programs have been

developed over the past 20 years to reduce the negative impact of having a brother or sister with a disability, there have been very few trials evaluating the efficacy of these interventions. Where outcome measures have been used, (e.g., McLinden et al., 1991; Phillips, 1999), the results have been promising in terms of better adjustment of siblings at post-test compared to control groups. However, Phillips provided the only methodologically rigorous controlled trial of an intervention for siblings. This study found evidence to support many positive outcomes for siblings attending the groups, such as a decrease in depression and anxiety symptoms as well as lower stress levels in relation to their sibling. However this study was unable to tease apart the effects of each component of the program.

There is also the need for clearly defined outcome measures and the inclusion of comparison groups. Only under these conditions can we determine the efficacy of the intervention. Piloting an intervention is important as it ensures that the program is easy to implement and socially valid. If the outcomes are positive, conducting an efficacy study is then required to ensure that the program produces reliable and generalisable outcomes that assist in the *positive* development of siblings.

The Mental Health Promotion National Action Plan (VicHealth, 1999) advocates the use of evidence-based practice when developing programs for children. They found many programs report a low level of research evidence. For example, 29 of the 44 programs reported in a recent Scoping

Project Report (AICAFMHA, 2001) had no research evidence to support their claims. Programs that are not evidence-based may not be producing the desired outcomes, or they may be doing more harm than good.

Study 2 involves a controlled trial of a pilot intervention that aims to reduce the impact of disability on older teenage siblings of children with intellectual disabilities. It also aims to promote better family functioning and more positive self perceptions in siblings. Thus, it is expected that the perceived effect of disability on siblings and their self esteem will positively increase.

As the Double ABCX model (McCubbin & Patterson, 1983) predicts an interaction between the family's perceptions of these stressors, their resources and their ability to cope, it is anticipated that by participating in the program siblings' families' resources and supports as a whole may increase. Four main hypotheses regarding the pilot intervention were thus proposed:

### *Hypothesis 1*

There will be a significant difference between the intervention and control group scores across all PED subscales at post-test after controlling for pre-test scores. Participants in the intervention group will have a significantly higher score on the *Positive Influence of Disability* subscale at post-test compared to the comparison group, while their scores on the *Family Differences*, *Worry About What Others Think* and *Lack of Time With Others*

subscales will be significantly lower than those of the control group at post-test, indicating better overall adjustment.

### *Hypothesis 2*

There will be a significant time x group interaction across each PED subscale and an overall main effect found for time. Participant scores on the *Positive Influence of Disability* subscale will increase between pre and post-test for the intervention group, while there will be no change across time for the comparison group. Participant scores on the *Family Differences, Worry About What Others Think* and *Lack of Time With Others* subscales will decrease across time, while there will be no change in participant scores in the comparison group across this times.

### *Hypothesis 3*

Family adjustment of the intervention group will significantly increase between Time 1 and Time 2.

### *Hypothesis 4*

The self-esteem of participants in the intervention group will significantly increase between Time 1 and Time 2.

## *Chapter 8: Study 2: The Efficacy of a Sibling Intervention*

Study 2 involved the development and controlled trial of an intervention aimed at assisting the positive adjustment of teenage siblings of children with an intellectual disability. This chapter describes the development of the intervention, and the methods used to evaluate it, including the recruitment and description of participants, and the materials and procedures. The results of the analyses are then presented along with a brief discussion of the results.

### **8.1 Development of the Intervention**

The review of interventions developed in past research along with the Double ABCX model (McCubbin & Patterson, 1983) provided a theoretical model in the development of the present program. There were 7 steps in its development:

1. A review of published and identified unpublished interventions for siblings of children with disabilities was conducted. Strategies and content that had been found to be acceptable to siblings and or families, or effective in promoting their wellbeing, were identified and checked against the theoretical model (see Chapter 7).
2. A list of aims and objectives for the intervention was then generated from the theoretical model, and intervention strategies were identified to match the objectives.

3. The intervention objectives and strategies were then sequenced into six group sessions.
4. Outcomes for each session were then developed, and activities designed to achieve each outcome, based on the strategies identified above, and the theoretical model. A detailed script for implementation of each activity and session was then written.
5. The first draft of the intervention was then sent to an expert panel of professionals working in disability and/or adolescence areas. Their feedback was incorporated with necessary amendments.
6. The intervention was refined in the light of this feedback, to meet group time guidelines, and to ensure that activities were appropriately sequenced to build on skills and knowledge developed in earlier activities and sessions.
7. The intervention was presented in two manuals - a *Facilitator Manual* and a *Participant Booklet*. The manuals were designed to be informative, clear, user-friendly, and age-appropriate for adolescent participants. The final intervention comprised six, one-and-a-half hour group sessions for teenage siblings.

#### 8.1.1 Outcomes of Interventions for Siblings

The overall aim of the intervention was to assist the positive adjustment of teenage siblings. McCubbin and Pattersons' (1983) Double ABCX model suggests that interventions that aim to positively influence the adjustment of family members of children with an intellectual disability, should target the

family's resources, such as social supports, along with family member's perception of the stressor. The research reviewed in Chapter 7 and the findings of Study 1 indicate that siblings of children with special needs experience greater levels of stress in their family lives (Senel & Akkk, 1996; Kirkman, 1985; Walton, 1993), and have unique concerns about their family and social lives (Bagenholm & Gillberg, 1991; Crnic & Leconte, 1986; Powell & Gallagher, 1993; Nesa, 1999). Accordingly, a number of interventions has been developed. The review of existing programs suggests a number of important content areas for future programs. These interventions have included strategies that aim to increase: sharing information about one's family (e.g., Houtzager et al., 2001); sibling's knowledge of disability/illness (e.g., Evans et al., 2001); understanding about what it's like to have special needs (e.g., Flynn & Meakin, 1989), recognition of differences (e.g., Summers et al., 1991); recognition of individual and sibling strengths (e.g., Lobato, 1985); expression of feelings (e.g., Strohm, 2001); coping strategies (e.g., McLinden et al., 1991) and; social skills (e.g., Flynn & Meakin, 1989). A list of aims and objectives for the intervention was generated from the theoretical model, and intervention strategies were identified to match the objectives. Thus, the present program drew from the common areas covered by past studies. These formed the outcomes for each session. Activities were designed to achieve each outcome, based on the strategies identified above, and the theoretical model. The specific outcomes of each session are presented in Table 8.1.

Table 8.1

*Objectives and Outcomes of Each Session*

| Group No. | Session Title                          | Objectives                                                                                                                                                                                                                               | Outcomes                                                                                                                                                                                                                                                                                                                       |
|-----------|----------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1         | Sharing My Story                       | <ul style="list-style-type: none"> <li>• Introduce themselves to each other</li> <li>• Siblings share their story with others</li> </ul>                                                                                                 | <ul style="list-style-type: none"> <li>• Siblings develop a rapport with each other</li> <li>• The development of a safe and supportive environment where siblings can share their stories and express their feelings</li> </ul>                                                                                               |
| 2         | Exploring Differences and Disabilities | <ul style="list-style-type: none"> <li>• Discuss the things that they have in common with their sibling and things they don't</li> <li>• Discuss what they know about their sibling's disability</li> <li>• Discuss strengths</li> </ul> | <ul style="list-style-type: none"> <li>• To explore the differences and similarities siblings have with their families and others</li> <li>• To build knowledge and understanding about disabilities</li> <li>• To enhance knowledge about personal strengths and the strengths of their siblings with a disability</li> </ul> |
| 3         | Exploring and Communicating Feelings   | <ul style="list-style-type: none"> <li>• Discuss different types of feelings</li> <li>• Discuss the roles of social support and barriers to accessing it</li> </ul>                                                                      | <ul style="list-style-type: none"> <li>• To enhance awareness of feelings regarding having a brother or sister with a disability</li> <li>• To enhance family communication regarding challenging situations</li> </ul>                                                                                                        |
| 4         | Coping Skills I                        | <ul style="list-style-type: none"> <li>• Present problem-solving steps</li> <li>• Engage in role-plays about difficulties siblings may face in order to practice problem-solving</li> </ul>                                              | <ul style="list-style-type: none"> <li>• To identify and access support when needed</li> <li>• To know and demonstrate problem-solving skills when facing challenging situations where participants may have some control over the outcome</li> </ul>                                                                          |
| 5         | Coping Skills II                       | <ul style="list-style-type: none"> <li>• Discuss and practice a range of coping skills</li> </ul>                                                                                                                                        | <ul style="list-style-type: none"> <li>• To identify and apply coping skills to deal with the more challenging times</li> </ul>                                                                                                                                                                                                |
| 6         | Finding Meaning                        | <ul style="list-style-type: none"> <li>• Reflect on information from past sessions</li> <li>• Rate enjoyment of the groups and what was learnt</li> </ul>                                                                                | <ul style="list-style-type: none"> <li>• Review and reflect on past learning</li> <li>• Integrate past sessions to help participants find meaning in their situation</li> <li>• Evaluate group intervention</li> </ul>                                                                                                         |

The first session incorporated sharing stories about family life, the second on sharing information about disabilities and exploring strengths. Expression of feelings was encouraged throughout each session, however session three emphasised siblings' feelings and allowed siblings to discuss ways of communicating these feelings to others. Coping skills including relaxation and exploring social supports was the focus of sessions four and five. The last session focused on the integration of information learnt to help siblings find meaning in their situation.

Activities were designed to achieve each outcome, based on what has worked in past interventions. A detailed script for implementation of each activity and session was then written. The draft of the intervention was then sent to an expert panel of four psychologists working in the disability or education sector. They provided feedback on content as well as presentation. Three of the psychologists had also worked with adolescents and were able to comment on the age-appropriateness of the intervention. Amendments to the intervention were then made incorporating the feedback. The intervention was refined to allow for group time, and to ensure that activities were appropriately sequenced to build on skills and knowledge developed in earlier activities and sessions as indicated by past research in the area. A participant manual was then produced to accompany to facilitator manual. The manuals were checked to ensure that they were clear, user-friendly and age-appropriate. The facilitator manual included handouts with information on intellectual disabilities, scenarios for role-plays,

relaxation scripts and *Parent Information Sheets*. The parent information sheets provided information on the content of each group session.

The aim of the sheets was to inform parents on sibling needs, to reinforce the skills covered in the group sessions at home and to generate discussion about the topics between parent and teenager. The intervention included six group sessions for teenage siblings.

## **8.2 Method**

### 8.2.1 Recruitment of Participants for the Intervention Group

Due to the inadequate participant numbers of past studies (e.g., Lobato, 1985; McLinden et al., 1991), extensive work focused on recruiting participants for the pilot intervention.

The participants were drawn from the sample of participants from the Disability Services Commission, described in Section 5.2.1 (p. 98). In addition advertisements seeking participants were published in newspapers such as: The Western Australian (the major daily newspaper for Western Australia); community newspapers around Perth such as the Canning Times, Western Suburbs Weekly and the Melville Times; and in newsletters sent to families through local disability organisations such as the Down Syndrome Association, IdEntity WA, Kalparrin and Activ News.

Radio advertisements were also conducted, with the researcher participating in radio interviews on two local radio stations - Curtin Radio and 6PR (Nightline). Awareness of the project was also established through staff at the Disability Services Commission of Western Australia. Staff included articles about the project in their newsletters to families in their area and many also sent letters to families explaining the project (see H Appendices). In addition, posters outlining the project were placed around DSC offices.

These advertisements asked families to contact the researcher directly if they were interested in the project or required further details. If the family met the inclusion criteria (they had a child with an intellectual disability below the age of 18 years and one or more children between the ages of 12 and 17 years), they were sent a letter asking them to indicate their preferences for the time, day and venue of the sibling group sessions (see Appendix I1). Families who did not meet the criteria for inclusion were thanked for their time and sent an information pack on sibling needs.

### 8.2.2 Intervention Group

The intervention was run with two groups of participants, at Disability Services Commission offices in two districts. Twenty-five siblings initially expressed an interest in the intervention and met the inclusion criteria. At the time of recruitment families were asked to nominate times and days that were suitable for siblings to attend. Group session times and venues were then developed based on the most popular times and days. Three

participants were unable to attend due to other commitments, and six families withdrew due to transport and work commitment problems, or sibling concerns (such as shyness over meeting others or not feeling that they needed help), leaving 16 participants in the intervention group. Two participants subsequently withdrew after the second group session because of overseas travel and travelling time to the sessions. This left 14 intervention group participants, 56% of the initial sample. One participant attended only three out of the six groups due to interstate travel. Thus, this participant's data were removed from the analysis. The sibling numbers over each recruitment phase are summarised in Figure 8.1.

### 8.2.3 Matched Comparison Group

Despite the wide advertising, there was not a sufficient number of participants recruited to randomise to a control group. The next best thing is a comparison group. This was possible because the time frame of testing in Study 1 was the same as the length of the intervention. Thus it was possible to use their data as comparison group data. Hence, a matched comparison group was formed in order to compare the effects of maturation and extraneous factors in the lives of teenage siblings of children with disabilities. Thirteen participants who had completed the PED measure on two occasions over approximately six weeks, (the same time period as the group intervention), in Study 1 formed the comparison group for Study 2. This comparison group was matched on age and sibling status (i.e. older or younger than their brother or sister with an intellectual disability).

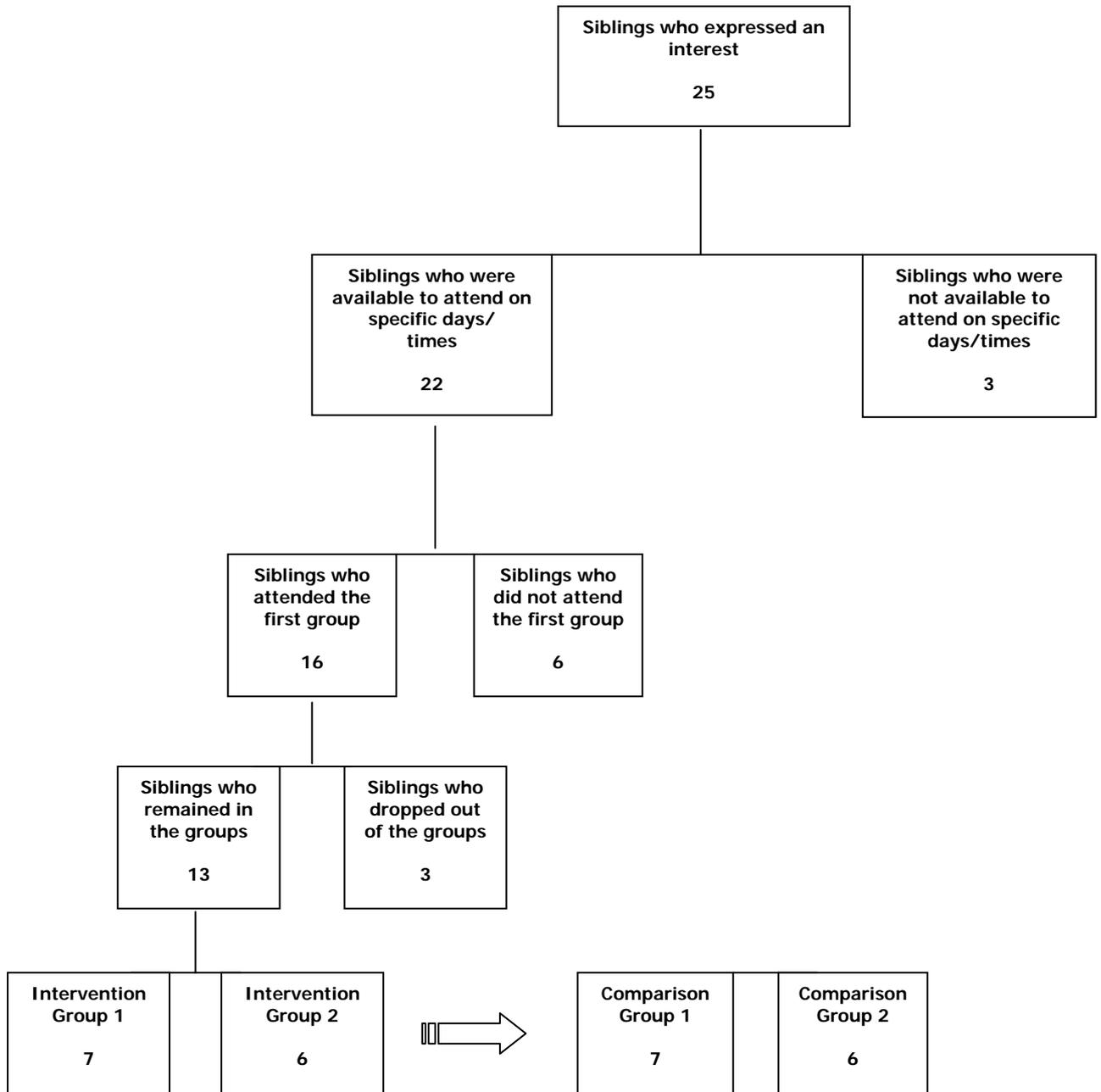


Figure 8.1 Siblings numbers over each recruitment phase.

Ten of the comparison group participants were also matched on gender. Pre-test comparisons (t-tests and chi-square) were conducted between groups on the demographic variables. The groups were equivalent at pre-test ( $p > .05$ ) on all variables except the support level required by the child with a disability in the family ( $p = .048$ ), with the intervention group having siblings with significantly lower support needs than those of the comparison group.

#### 8.2.4 Participant Characteristics

Participants in the intervention group were 13 siblings of children with an intellectual disability (6 females, 7 males) aged between 12 and 17 years ( $M = 14.29$ ,  $SD = 1.46$ ). These siblings were from 11 families, with eight being older than their sibling with an intellectual disability, five being younger than the child with an intellectual disability and all living in the Perth or Outer Perth Metropolitan Area. Participants in the comparison group were 13 siblings of children with an intellectual disability (8 females, 5 males) aged between 12 and 17 years ( $M = 14.32$ ,  $SD = 1.59$ ). These siblings were from 13 families, with eight being older than their sibling with an intellectual disability, five being younger than the child with an intellectual disability and all living in the Perth or Outer Perth Metropolitan Area.

Each participant had only one brother or sister with a disability. Ten intervention group participants lived at home with at least one shared biological parent of the child with a disability whilst two children were

adopted and one child was a stepsibling of the child with a disability. Twelve of the comparison group participants lived at home with at least one shared biological parent of the child with a disability whilst one child was living with a foster family.

#### 8.2.5 Characteristics of the Child with an Intellectual Disability

Nine intervention group participants had a brother with an intellectual disability and four had a sister with an intellectual disability, all aged between 3.50 and 19 years of age ( $M = 11.99$ ,  $SD = 5.10$ ). Twelve comparison group participants had a brother with an intellectual disability and one had a sister with an intellectual disability, all aged between 5.08 and 15.83 years of age ( $M = 11.95$  years,  $SD = 3.40$ ). The diagnoses of these children are displayed in Table 8.2.

The overall support scores (as described in Study 1) ranged from 1 to 4 for both groups and had a mean of 2.00 ( $SD = 1.15$ ) for the intervention group and 2.89 ( $SD = .90$ ) for the comparison group. Over 45% of parents ( $n = 6$ ) in the intervention group reported that their child required "occasional support in two or more areas of daily living" while over 45% of parents ( $n = 6$ ) in the comparison group reported that their child required "support in most areas of daily living".

Table 8.2

*Primary Diagnoses of Child with a Disability as Reported By Parents (N = 26)*

| Diagnoses                       | Group        | Number |
|---------------------------------|--------------|--------|
| Of unknown cause                | Intervention | 6      |
|                                 | Comparison   | 5      |
| Down syndrome                   | Intervention | 4      |
|                                 | Comparison   | 0      |
| Epilepsy                        | Intervention | 1      |
|                                 | Comparison   | 0      |
| Autism Spectrum Disorder/Autism | Intervention | 2      |
|                                 | Comparison   | 3      |
| Hydrocephalus                   | Intervention | 0      |
|                                 | Comparison   | 1      |
| Marden Walker Syndrome          | Intervention | 0      |
|                                 | Comparison   | 1      |
| Sturge Webber Syndrome          | Intervention | 0      |
|                                 | Comparison   | 1      |
| Severe Dyspraxia                | Intervention | 0      |
|                                 | Comparison   | 1      |
| Tetrasomy 18P                   | Intervention | 0      |
|                                 | Comparison   | 1      |

Eight participants in the intervention group and five participants in the comparison group went to the same school as their brother or sister with a disability at some stage of their lives. Time spent at school together ranging from less than one year up to eight years for both groups, with a mean of 1.88 years ( $SD= 2.55$ ) for the intervention group and 1.16 years ( $SD = 2.53$ ) for the comparison group. Only one participant in the intervention group

and two participants in the comparison group were currently attending the same school as their brother or sister with an intellectual disability.

### 8.2.6 Parental Characteristics

The age of the mothers of children in the intervention group ranged from 35.83 to 61.50 years ( $M = 43.64$ ,  $SD = 6.82$ ), while the age of those in the comparison group ranged from 34.50 to 47.85 years ( $M = 42.95$ ,  $SD = 3.93$ ). The age of the fathers in the intervention group ranged from 28.40 to 63.92 years ( $M = 43.64$ ,  $SD = 6.82$ ) and those in the comparison group ranged from 37.00 to 55.07 years ( $M = 46.08$ ,  $SD = 5.68$ ). The marital status of parents in both groups along with the distribution of the education level of mothers and fathers outlined in Table 8.3.

The level of education of parents of participants in the intervention group was higher than the overall level of education of parents in Study 1 (particularly for the intervention group). For example, 46.15% of both mothers and fathers from the intervention group had attended university compared to an average of 29.07% of mothers and 31.65% of fathers across Study 1.

Table 8.3

*Marital Status and Education Levels of Mothers and Fathers in Study 2*

|                        | Mother       |         | Father       |         |
|------------------------|--------------|---------|--------------|---------|
|                        | Intervention | Control | Intervention | Control |
| <i>Marital Status</i>  |              |         |              |         |
| Married                | 7            | 9       | 7            | 9       |
| Divorced               | 3            | 0       | 4            | 0       |
| Separated              | 2            | 3       | 2            | 2       |
| Defacto                | 1            | 0       | 0            | 0       |
| Single                 | 0            | 0       | 0            | 0       |
| Missing                | 0            | 1       | 0            | 2       |
| <i>Education Level</i> |              |         |              |         |
| Yr 10                  | 2            | 4       | 2            | 3       |
| Yr 11                  | 0            | 1       | 0            | 0       |
| Yr 12                  | 2            | 0       | 2            | 2       |
| TAFE*                  | 3            | 2       | 2            | 2       |
| University             | 6            | 4       | 6            | 3       |
| Other                  | 0            | 0       | 0            | 1       |
| Missing                | 0            | 2       | 1            | 2       |

\*TAFE = Technical and Further Education institution

### 8.3 Materials

Participants in both groups were sent an information package, which included a confirmation sheet and an information sheet for families (see Appendices I2 and I3), a consent form (intervention families only) that provided permission for children to participate in the groups (see Appendix I4), and a demographic questionnaire for parents to complete (see Appendix I5).

### 8.3.1 Perceived Effect of Disability Measure

The Perceived Effect of Disability measure (developed in Study 1, see Appendix J1) involved siblings rating the extent to which they believed having a brother or sister had affected their lives. There are 40 items in total across four subscales, *Positive Influence of Disability*, *Family Differences*, *Worry About What Others Think* and *Lack of Time With Others*. Higher scores on *Positive Influence of Disability* are more positive while lower scores on the other three subscales are more positive. Items require forced choice responses of "True", "Mostly True", "Mostly False" and "False". The internal consistency (see Chapter 5) for the total scale was .84. The internal consistency was .87 for Part 1 of the measure and .85 for Part 2 of the measure and .92, .84, .87 and .76 for each of the respective subscales. Test-retest reliability for the measure has been conducted over a six-week period with Pearson correlation coefficients of .87 for the total scale, .84 for Part 1, .84 for Part 2 and .80, .88, .79 and .84 for each of the respective subscales.

In Study 1, this questionnaire was designed for use with *older* teenager siblings of children with an intellectual disability. However, many interested families sent back completed questionnaires from *younger* siblings (18 siblings in total). To determine the appropriateness of the measure for this population, the data were analysed to investigate similarities between older and younger siblings. Cronbach's alpha coefficients revealed that the measure had high internal consistency for this group (Total  $\alpha = 0.85$ ) along

with high-moderate internal consistency for each of the respective parts and subscales (Part 1  $\alpha = .76$ , Part 2  $\alpha = .86$ , Positive Influence of Disability  $\alpha = .72$ , Family Differences  $\alpha = .84$ , Worry About What Others Think  $\alpha = .86$ , Lack of Time With Others  $\alpha = .83$ ). These analyses provide evidence that the measure is reliable for younger siblings (see Appendix J2) as well as older siblings. Furthermore, the measure has demonstrated high content and face validity (see Study 1).

### 8.3.2 Self Description Questionnaire - II

The Self-Description Questionnaire II (Marsh, 1990) is a 102-item scale for adolescents with 11 subscales in total covering academic self-concept, non-academic self-concept and general self-concept. Items are answered: "False", "Mostly False", "More False Than True", "More True Than False", "Mostly True" or "True". Individual subscales can be administered independently and thus to ensure participants were not burdened by an overly long assessment only the *Opposite-Sex Relations*, *Same-Sex Relations*, *Parent Relations*, *Emotional Stability* and *General Self* subscales were administered (47 items in total). Cronbach's alpha coefficients for each subscale indicated high internal consistency (Opposite-Sex Relations  $\alpha = .90$ , Same-Sex Relations  $\alpha = .86$ , Parent Relations  $\alpha = .87$ , Emotional Stability  $\alpha = .83$  and General Self  $\alpha = .88$  respectively). Marsh reports the test-re-test over a 7-week interval as varying between 0.72 and .85 for these subscales. The measure displays good construct validity, with scores correlated with

those of other self-concept measures and variables such as academic achievement (Marsh).

### 8.3.3 McMaster Family Assessment Device

The McMaster Family Assessment Device (Epstein, Baldwin, & Bishop, 1983) is a multidimensional measure of family functioning. There are seven subscales in the measure, however only the 12-item *General Functioning* (GF) subscale was used for the purposes of this study. This subscale has shown good internal consistency across a number of populations. For example, Bihun, Wanbolt, Gavin and Wanbolt (2002) reported a Cronbach's alpha reliability coefficient of .79 with their sample of children over 12 years of age. Test-retest reliability over a one-week period has been reported as .71 by Miller, Epstein, Bishop and Keitner (1985). Miller et al. reported that the measure has moderate correlations with other measures of family functioning such as family stress. A clinical cut-off score of 2.2, recommended by Miller et al., was used. The researchers report this cut-off as having 87% rate of sensitivity 45% specificity and as well as a high rate (83%) of diagnostic confidence.

### 8.3.4 Social Validity Questionnaires

#### *Facilitator Materials*

The facilitator kept a process logbook recording the content covered each week, and any important issues/concerns raised during the groups. Both facilitators and co-facilitators completed evaluations after each group (see

Appendix K1). These evaluation forms asked facilitators to indicate if all activities/discussions were completed, information about any modifications that were made to the group session, whether the overall goals of the session were reached, if there were any difficulties in implementing any of the activities or discussions, and whether there were any successes in implementing any of the activities or discussions in the group. Facilitators were also asked to record the number of sessions participants attended, their level of participation (see Appendix K2) and complete an overall evaluation at the completion of the groups (see Appendix K3). The overall evaluation form asked facilitators to indicate if all group sessions were completed, if the overall goals were reached and to list any specific difficulties or successes in the implementation of group sessions. In addition facilitators were asked to comment on the structure of the group sessions in general, and on the usefulness and clarity of the facilitator manual.

#### *Participant Questionnaires*

Participants were asked to answer five qualitative questions at the end of each group session (the questions were developed by the researcher see Appendix K4) asking them what they learnt, how this will help them and their sibling, what activities they enjoyed the most/least and what they would like to change about the session. The overall evaluation of the program (see Appendix K5) consisted of four qualitative questions asking participants what the most important thing they learnt, what was their favourite and least

favourite group session and what had changed since they had been attending the group.

### *Parent Questionnaire*

The parent questionnaire (see Appendix K6) was based on that developed by Strohm (2003) for parents of siblings attending sibling program. The questionnaire consists of seven questions, six of which have dichotomous responses, though all allow qualitative comments. The questionnaire asks parents if their child: talked about the group sessions, enjoyed the group sessions, if any activities made a strong impression or if their child was upset/concerned about anything. In addition there were questions about whether they had noticed any changes since their children had attended the group sessions, if they would like their child to participate in another group and if they have any suggestions about improvements to the program.

### 8.3.5 Intervention Program Materials

Facilitator materials included Facilitator and Participant Manuals (see Volume 2).

### *Facilitator Manual*

The facilitator manual consisted of 66 pages containing a rationale for the group program, aims and objectives, tips on setting up the groups, such as the timing of the groups and transport, food and other materials, as well as managing disruptive behaviour. The manual also included the procedure for

implementing each group session and appendices containing additional materials required to implement the group sessions such as an information sheet about intellectual disabilities, scenarios for role-plays, relaxation scripts, and the *Parent Information Sheets* (discussed below). The group sessions consisted of discussions, paper and pencil activities such as drawing, or writing, games and role-plays. First, the activities included those aimed at fostering rapport and group cohesion. The activities also included the identification and expression of feelings, the identification of similarities and differences between siblings, identification of strengths, discussion about the role of social support, identification of social support networks, and coping strategies, such as relaxation skills, along with reflections on siblings' progress over the group sessions.

In order to determine the extent to which the intervention was implemented a number of procedures advocated by Sidani (1998) were followed. These included the following: 1) all intervention activities and discussions for this pilot intervention were written in detail, 2) the specific sequence in which the activities and discussions should be presented was provided, 3) scripts were provided for most activities/discussions in order to avoid drift.

#### *Participant Booklet*

The participant booklet was developed to complement the facilitator manual. The booklet consisted of 39 pages containing a rationale for the group program, aims and objectives, activities that required participants to record

their feelings and/or experiences, a list of resources, the social validity questionnaires (see pg. 176) and pages where they could record the contact details of other group members and notes.

### *Parent Materials*

To facilitate parental knowledge of the program content, foster discussion between parent and teenager and promote generalisation of skills to the home environment, parents of children in the intervention group were given a *Parent Information Sheet* at the end of each group session. These information sheets explained the content covered in each group session along with tips for the parents (see Appendix 4, Volume 2).

Last, siblings attending the groups were provided with afternoon tea. Past literature has shown that participants enjoy having snack time during group programs and that this enhances their satisfaction with the group process (Dyson, 1998).

## **8.4 Procedure**

### 8.4.1 Final Recruitment

The advertisements described in Section 8.2.1 (pg. 164) asked families to contact the researcher directly if they were interested in the project or required further details. If the family met the inclusion criteria they were sent a letter asking them to indicate their preferences for the time, day and

venue of the sibling groups (see Appendix I1). Families who did not meet the criteria for inclusion were thanked for their time and sent an information pack on sibling needs.

#### 8.4.2 Consent

Families who had confirmed their allocation to a group were sent a letter with the details of the group (see Appendix I2), an information sheet on the research project (see Appendix I3), a consent form giving children permission to participate (see Appendix I4) and a demographic form (see Appendix I5). Participant consent was obtained verbally at the first group session. A telephone call was made to all families a few days before the first group session to answer queries or address concerns. The main concern raised by parents was regarding their child's rights to withdraw from the group sessions if they "didn't like them". It was restated to families that their child was free to withdraw from the study at any stage without any repercussions.

#### 8.4.3 Data Collection

Participants in the intervention group were administered the PED measure at the beginning of the first group session (pre-test) and at the end of the last group session (post-test). As mentioned in Section 8.2.3 (pg. 166) participants in the comparison group completed the PED measure over the same time frame in Study 1. In addition, participants in the intervention group completed the Self-Description Questionnaire II (Marsh, 1990) and the

McMaster Family Assessment Device (Epstein et al., 1983) at pre and post-test. They also provided qualitative feedback at the end of each group session along with an overall evaluation of the program after it had been completed (see Section 8.3.4, pg. 176). In addition, parents provided qualitative feedback via a questionnaire administered at the end of the intervention (see Section 8.3.4, pg. 177).

#### 8.4.4 Implementation

The researcher, a registered Psychologist, was the main facilitator of the intervention. A facilitator and co-facilitator assisted with the organisation and overall facilitation of the group sessions. Furthermore, Corey and Corey (1992) believe that benefits of a co-leadership model include reduced risk of burnout, increased opportunity to process feelings after the group session, and increased ability to balance participation of group members. Hence, one facilitator ran the program with both groups of participants to ensure no content drift, whilst separate co-facilitators were used for each group of participants to ensure that the intervention effects were due to the content of the intervention and not purely to the skill and style of the facilitators involved. Two registered Clinical Psychologists from the Disability Services Commission, who had extensive experience in running adolescent groups, co-facilitated the group sessions. Facilitators followed the procedures outlined in the *Facilitator Manual* (see Volume 2) for each group session.

## 8.5 Results

### 8.5.1 Data Analysis

The data were analysed using SPSS for Windows (Version 11.5).

First, a two-group analysis of covariance was conducted, with participant pre-test scores used as the covariate. Next two-way mixed design SPANOVAs were conducted to determine the effects of time on the PED subscale scores for each group. Last, separate one-way repeated measures analyses of variance were conducted to establish whether participant scores had changed over time on the self-esteem and family functioning measures. An alpha level of .05 was used to test significance throughout. As this intervention was innovative and exploratory, it is important it identify any potential intervention effects if they are present. Hence, the consequences of making a Type II error are more serious than making a Type I error. For this reason no corrections were made to the alpha level for multiple univariate tests.

As the matched comparison group was formed from Study 1 participants who had not completed the self-description or family functioning measures, there was no comparison group for the last two outcomes.

### 8.5.2 Assumption Testing

#### *ANCOVAs*

The assumptions underlying the two-group Analysis of Covariance (ANCOVA) include normality of dependent variables and covariate scores, homogeneity

of variance, linearity between the dependent variable and covariate and homogeneity of regression slopes (Coakes & Steed, 2003). Examination of the scatterplots confirmed that a linear relationship occurred between the covariates and dependent variables. Levene's test for equality of error variance was conducted as part of the ANCOVA and these were not found to be significant ( $p > .05$ ) for either group on any of the subscales. This indicates that the assumption of homogeneity of variance was met. Tests of significance were conducted on the dependent variable and covariate using sums of squares. These analyses revealed no violation to the assumption of homogeneity of regression slopes. Furthermore, Kolomogorov-Smirnov and Shapiro-Wilks statistics were computed for each of the covariate and dependent variables for each group. The significance level was greater than .05 across the all four subscales for both groups, indicating that the normality assumption had been met.

### *SPANOVAs*

The assumptions underlying the SPANOVA include those underlying the ANOVA such as normality, homogeneity of variance as well as the additional assumption of homogeneity of intercorrelations (Coakes & Steed, 2003). Kolomogorov-Smirnov and Shapiro-Wilks statistics were computed for pre and post-test scores across each subscale for each group. The Shapiro-Wilks statistic conducted on the post-test *Positive Influence of Disability* scores was less than .05 for the comparison group, indicating that the normality assumption was not met. This should be taken into account when reviewing

the results. The significance level was greater than .05 across the all other subscales at pre and post-test for both groups. Levene's test for equality of error variance was conducted and these statistics were not significant ( $p > .05$ ) across any of the subscales, indicating that the homogeneity of variance assumption was met. Last, the assumption of homogeneity of intercorrelations was tested using the Box M statistic. Homogeneity was present as indicated by a non-significant ( $p > .001$  as recommended by Coakes & Steed) Box M statistic across all four of the SPANOVAs conducted.

#### *Repeated Measures ANOVAs*

Prior to conducting the one-way repeated measures Analyses of Variance (ANOVAs), Shapiro-Wilks and Kolmogorov-Smirnov analyses were conducted on each of the scales and subscales. The significance level for these statistics was above .05 across the subscales on the self-esteem and family functioning measures, indicating that the normality assumption was met. Levene's test for equality of error variance was conducted and these statistics were not significant ( $p > .05$ ) across any of the subscales, indicating that the homogeneity of variance assumption was met.

### 8.5.3 Results- Primary Hypotheses

#### *Hypothesis 1*

There will be a significant difference between the intervention and comparison group scores across all PED subscales at post-test after controlling for pre-test scores. Participants in the intervention group will have a significantly higher score on the *Positive Influence of Disability* subscale at post-test compared to the comparison group, while their scores on the *Family Differences*, *Worry About What Others Think* and *Lack of Time With Others* subscales will be significantly lower than those of the comparison group at post-test, indicating better overall adjustment.

There were no significant differences between the intervention and comparison group scores at post-test on the *Positive Influence of Disability* subscale,  $F(1,24) = 1.178, p = .289$ ; the *Family Differences* subscale,  $F(1,24) = 2.719, p = .113$ ; *Worry About What Others Think* subscale  $F(1,24) = .115, p = .738$ ; or *Lack of Time With Others* subscale  $F = 1.353, p = .056$ . The means and standard deviations of the intervention and comparison group scores at pre and post-test are presented in Table 8.4.

Table 8.4

*Descriptive Statistics for Pre and Post-Test Data For Intervention and Comparison Group on the Perceived Effect of Disability Measure (N = 26)*

| Subscales                        | Group        | Time | <i>n</i> | <i>M</i> | <i>SD</i> |
|----------------------------------|--------------|------|----------|----------|-----------|
| Positive Influence of Disability | Intervention | Pre  | 13       | 30.53    | 8.97      |
|                                  |              | Post | 13       | 32.46    | 8.53      |
|                                  | Comparison   | Pre  | 13       | 31.60    | 8.13      |
|                                  |              | Post | 13       | 30.72    | 8.99      |
| Family Differences               | Intervention | Pre  | 13       | 12.20    | 5.27      |
|                                  |              | Post | 13       | 13.54    | 5.91      |
|                                  | Comparison   | Pre  | 13       | 12.38    | 6.31      |
|                                  |              | Post | 13       | 11.17    | 5.23      |
| Worry About What Others Think    | Intervention | Pre  | 13       | 12.46    | 9.44      |
|                                  |              | Post | 13       | 10.20    | 8.60      |
|                                  | Comparison   | Pre  | 13       | 10.24    | 7.07      |
|                                  |              | Post | 13       | 9.68     | 6.61      |
| Lack of Time With Others         | Intervention | Pre  | 13       | 3.77     | 3.19      |
|                                  |              | Post | 13       | 5.13     | 4.00      |
|                                  | Comparison   | Pre  | 13       | 4.54     | 4.25      |
|                                  |              | Post | 13       | 5.06     | 4.27      |

### *Hypothesis 2*

There will be a significant time x group interaction across each PED subscale and an overall main effect found for time. Participant scores on the *Positive Influence of Disability* subscale will increase between pre and post-test for the intervention group, while there will be no change across time for the comparison group. Participant scores on the *Family Differences*, *Worry*

*About What Others Think* and *Lack of Time With Others* subscales will decrease across time, while there will be no change in participant scores in the comparison group across this times.

The results of the SPANOVAs indicated that there was no significant interaction between time and group on *Positive Influence of Disability* subscale,  $F(1,24) = 1.331, p = .260$ , *Family Differences* subscale,  $F(1,24) = 2.459, p = .130$  or *Worry About What Others Think* subscale,  $F(1,24) = .411, p = .527$  or *Lack of Time With Others*  $F(1,24) = 1.443, p = .241$  scores.

There were no main effects for time on the *Positive Influence of Disability* subscale,  $F(1,24) = .186, p = .670$ , *Family Differences* subscale,  $F(1,24) = .007, p = .936$  or *Worry About What Others Think* subscale,  $F(1,24) = 1.135, p = .297$ . These subscale scores did not change significantly from pre to post-test.

There was a significant main effect for time on the *Lack of Time With Others* subscale  $F(1,24) = 7.256, p = .013$ . This effect is in the negative direction, indicating that both intervention and comparison group participants reported having less time with others as a result of having a sibling with a disability at post-test as compared to six weeks previously at pre-test.

#### 8.5.4 Results- Secondary Hypotheses

##### *Hypothesis 3*

Family adjustment will significantly increase between pre-test and post-test.

There were no significant differences between participants scores at pre and post-test,  $F(1,12) = .501, p = .493$ . Table 8.5 presents the mean<sup>12</sup> and standard deviations of the participants' pre and post-test scores on the General Functioning Scale, indicating that adolescents' perceptions of family functioning were stable over time.

##### *Hypothesis 4*

Participants' self-esteem will significantly increase pre- to post-test.

The means and standard deviations of participants' scores for each of these subscales are presented in Table 8.7. This table shows that participant scores increased at post-test for the *Parent Relations*, *Emotional Stability* and *General Self* subscales. However, there were no significant differences between participants' pre and post-test scores on any of the subscales:

*Opposite Sex Relations*,  $F(1,12) = .854, p = .374$ ; *Same-Sex Relations*,  $F(1,12) = 1.114, p = .312$ ; "Parent Relations" subscale,  $F(1,12) = .002, p = .968$ ; *Emotional Stability* subscale,  $F(1,12) = 2.131, p = .170$ ; and *General Self* subscale,  $F(1,12) = 2.016, p = .181$ .

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<sup>12</sup> Lower scores indicate better overall family functioning

Table 8.5

*Descriptive Statistics for Pre and Post-Test Data on the General Functioning Scale of the McMaster Family Assessment Device and the Self-Description Questionnaire (N = 26)*

|                                  | Pre/Post | <i>n</i> | <i>M</i> | <i>SD</i> |
|----------------------------------|----------|----------|----------|-----------|
| General Functioning Scale scores | Pre      | 13       | 1.76     | .58       |
|                                  | Post     | 13       | 1.83     | .59       |
| Opposite Sex Relations scores    | Pre      | 13       | 28.38    | 7.65      |
|                                  | Post     | 13       | 27.06    | 7.20      |
| Same Sex Relations scores        | Pre      | 13       | 43.00    | 4.12      |
|                                  | Post     | 13       | 41.54    | 6.73      |
| Parent Relations scores          | Pre      | 13       | 40.12    | 6.29      |
|                                  | Post     | 13       | 40.19    | 5.91      |
| Emotional Stability scores       | Pre      | 13       | 40.08    | 10.93     |
|                                  | Post     | 13       | 42.15    | 9.08      |
| General Self scores              | Pre      | 13       | 49.21    | 8.02      |
|                                  | Post     | 13       | 51.39    | 5.46      |

#### 8.5.5 Social Validity - Qualitative Feedback

Qualitative feedback was collected from participants and facilitators after each group session as well as at the completion of the intervention. A summary of overall changes observed and facilitator ratings of the success of the overall intervention are presented below.

#### 8.5.5.1 *Participant Feedback on Group Outcomes*

Overall the main skill reported by participants during the program was an increase in coping skills ( $n = 7$ , 53.8%). Some participants also reported that they had a better understanding about disabilities ( $n = 3$ , 23.1%).

Examples of comments regarding coping skills learnt by participants include:

- "About understanding a disability that a sibling has and about how others and you deal with problems and also giving an insight into how life is like for them"
- "How to deal with stress"
- "Ways to deal with problems, I found them particularly useful (though I already knew some of them) and have already used a couple of the methods"
- "That there are other people who are going through the same kinds of things and different ways to cope with different situations"
- "How to act when you're in difficult situations such as how to tell your friends also what it means to be a sibling"
- "It's been really good because now I feel like I can be more open. I have actually had a few bad experiences with people teasing my brother and also teasing me about my brother. This has taught me to face the situation, to not be shy and to remain strong at all times"
- "Coping skills"

In regards to learning about disability, participant responses included:

- “That everyone is different and shouldn’t be teased”
- “How to sort of understand situations for my sister and me”
- “To understand the feelings of other people with younger or older siblings. Also how to cope with different feelings I might have relating to my sibling with a disability”

Other comments about positive outcomes resulting from the groups included:

- “Not to get angry and shout at her (not that I did)”
- “That there are others in similar situations”
- “How to bring up sibling disability to tell friends”

#### *8.5.5.2 Participant Feedback on Change*

There were three areas of change reported by participants. First, some ( $n = 6$ , 46.2%) siblings felt that their attitude towards their sibling had changed since they had been attending the group sessions. Comments included:

- “My attitude towards my friends and brother [has changed]”
- “I’ve learned more about my brother”
- “I feel I can accept my brother and his disability- I am now more comfortable”
- “I have respected my sibling more”
- “How more important my brother is”
- “I respect my brother more”

Two participants (15.4%) reported that their attitude towards disability in general had changed:

- “I have started thinking about how life is like for the person with a disability and how I can spend my time with them usefully and how I can help to improve their quality of life”
- “I know more about other disabilities and the things others go through”

Others ( $n = 4$ , 30.8%) said that they were more skilled to deal with problems that occur:

- “I can cope better with situations that I couldn’t before”
- “I have found I am more patient”
- “I think I’ve become more patient and more able to deal with problems”
- “How to act in dilemmas with your sibling, how other siblings feel and what my responsibilities are as a sibling”

Finally, one sibling simply commented that attending the groups had changed their overall “outlook on life”.

#### *8.5.5.3 Participant Feedback on Most and Least Enjoyable Group Session*

Participant responses in regards to the most enjoyable group session indicated that the first covering “Sharing My Story”, was the most popular ( $n$

= 4, 30.8%). While one participant explained that this was because “we met each other and have become quite cool friends since”, a reason for another participant was “because we didn’t do work”!

Group sessions 2, 4 and 6 - “Exploring Differences and Disabilities”, “Coping Skills 1” and “Finding Meaning” were rated equally by participants as most enjoyable ( $n = 2$ , 15.4% each group). Comments included:

- “Week two because it gave me a chance to share my own experiences and learn about other disabilities”
- “Probably the ‘problem solving’ week- the week where we learnt different techniques on how to deal with certain situations. I benefited a lot from that I think”
- “The week were we did acting because it was fun and I learnt stuff from it”
- “Week 6 because everyone knew each other so they were relaxed.”

One participant found “Coping Skills 2” as the most enjoyable “because it helped me to learn how to relax and keep my cool in difficult situations. It also helped me to learn how to understand that these problems can be solved”. Another participant commented that all of the groups were equally enjoyable “Plus [I enjoyed] meeting different people” and one sibling reported “eating and learning about others and the siblings” was the most enjoyable part of the groups.

While group session 3 “Exploring and Communicating Feelings” was not rated as the most enjoyable by any participants, it was also not mentioned as being the least enjoyable. Group session 4 “Coping Skills 1” was rated as the least enjoyable activity by four participants (30.8%) with the main reason being participants not feeling comfortable or enjoying acting – “Probably the role plays- I hate acting!! I liked watching other plays though”. Group sessions 1 and 6 (“Sharing My Story” and “Finding Meaning”) were each rated as least enjoyable by one participant each (7.7%). Reasons included:

- “The first because I was unfamiliar and I didn’t know anyone”
- “The last because we may never talk again”

Group session 5 “Coping Skills 2” was also rated as least enjoyable by one participant “because I missed it”. Six participants (46.2%) reported that they enjoyed all group sessions and therefore couldn’t rate any group session as the least enjoyable.

#### *8.5.5.4 Parent Feedback on the Groups*

All of the parents reported that their children enjoyed the program and many ( $n = 9$ , 69.2%) reported that their child talked to them about the group sessions and most indicated they would like their child to participate in another sibling group at some stage ( $n = 9$ , 69.2%). The majority ( $n = 11$ , 91.67%) of parents noticed changes in their child since attending the group

sessions, with two areas of change emerging - increased tolerance ( $n = 6$ , 46.2%) and communication skills ( $n = 2$ , 15.4%).

In regards to increased tolerance, parents' comments included:

- "She has always been positive, but she has become that little bit more accepting of his disability. I think she is more at ease in relation to informing friends of his disability"
- "A little more tolerant, trying to understand unusual behaviour not just teasing"
- "He has seemed less annoyed with his sister since the course"
- "He is probably a little more tolerant"
- "Trying to explain to her circumstances [*sic*] a little more tolerant (sometimes)"
- "I noticed a definite change after each session - he was very positive with his brother and very mindful about what he can do"

One parent noted that since attending the group sessions her child was "more able to communicate to mum about the child's disability" and another commented "Both girls felt that they had learnt better strategies to deal with their brother when he doesn't listen etc. They are very good at discussing their feelings." One parent reflected that since attending the group sessions her child - "does appear more positive...maybe he is just realising he is not the only sibling out there".

#### *8.5.5.5 Implementation Fidelity*

In total, approximately 80% of the overall content was covered for each group of participants with a range of 50% - 100% of each group session. While some activities were not implemented in the allocated group session, due to lack of time, they were set as homework tasks or implemented the week after. For example, due to lack of time, in group session 1, the "Picture of My Family" activity was set as a homework task for one of the participant groups and then discussed the next week. In group session 2 the "Strengths" and "Things I Can Do..." worksheets were discussed, however unable to be completed in either group of participants due to time constraints. Nevertheless participants were asked to complete these activities for homework and then discuss the worksheets during the next group session. In group session 5 "Coping Skills 2", the activity "Coping Skills in Practice" was not implemented in full, due to lack of time. Thus, the relaxation skills were discussed and a brief demonstration of progressive muscle relaxation and breathing exercises was conducted rather than a complete practice of each of the skills.

#### *8.5.5.6 Facilitators Rating of the Overall Success of the Intervention*

Facilitators commented on all aspects of the intervention. One facilitator noted that it was "great for kids to be aware of issues for other kids in similar situations and to meet with each other" and another noted, "Every session was successful. The group got to know each other really well and could talk openly about emotions about siblings and family" and another reported "in

general activities flowed nicely from one to the other and participants seemed to enjoy them". The facilitators found the only implementation difficulty to be keeping the group on task and dealing with disruptive behaviour. The manuals were found to be useful and clear, and the overall group session structure was good. One facilitator noted that it was best not to run the program over the school holidays and another noted that with lower participant numbers, group cohesiveness was formed quickly. In addition, it was suggested that the program could be more intensive, extending over eight weeks.

All three facilitators agreed that the outcomes of the intervention were met. One remarked - "I think the program went very well considering this is a new program... Overall, I think it is an excellent program with heaps of potential and very beneficial to families with disabilities." Another commented, "All participants appeared to gain a lot from the groups - some parents commented on the benefits - most didn't want to leave at the end!! And wanted to meet again." Overall, the facilitators of both groups reported a number of implementation successes.

## **8.6 Summary**

Overall feedback from participants indicated that the main gains from the groups were learning information about disability (23.1%) and problem solving (53.8%). Many siblings reported an improved attitude towards their

sibling or disability in general (61.5%), and increased problem-solving skills (30.8%). Parents reported that they mainly observed an increase in siblings' tolerance (46.2%) and communication skills (15.4%). All of the parents reported that their children enjoyed attending the groups and facilitators noted implementation successes. Hence, qualitative data provided evidence for the social validity of the intervention.

Contrary to expectations there were no significant differences between the intervention and comparison group scores at post-test and no significant time x group interactions found on any of the PED subscales. The only main effect found was for time on the *Lack of Time With Others* subscale.

Participants' perceptions of their lack of time with others were higher at post-test for both groups, indicating a more negative effect over time.

Furthermore, teenage siblings attending the intervention group reported no significant changes in the family functioning or self-descriptions from pre to post-test. As the comparison group did not complete these assessments it was not possible to determine if this is an indication of success or not. It may be that as the impact of disability on siblings' increases, family functioning and sibling self-esteem declines. If this were the case then stability in family functioning and self-esteem would be a positive result.

## *Chapter 9: Discussion of Study 2*

The intervention was found to be easy to implement, and teenagers, parents, and facilitators expressed satisfaction with its content, structure, format and outcomes. Qualitative feedback from participants, parents and facilitators suggested improvements in attitudes and aspects of family life for siblings of children with an intellectual disability. These results provide evidence of the social validity of the intervention. However, the quantitative data did not support the outcome efficacy of the intervention. None of the four hypotheses relating to the quantitative data were supported. This chapter will explore the Study 2 hypotheses and compare the results of this study with that of past research. The limitations and implications of the research will then be discussed along with the implications for service delivery.

### **9.1 Hypotheses**

The efficacy of the intervention was investigated in terms of reducing the negative effects of disability on siblings using the new PED measure. A significant difference between the intervention and comparison groups was expected at post-test on each subscale of PED. However, no group by time interactions were found. The only significant main effect found was a time effect for the *Lack of Time With Others* subscale, with both groups reporting significantly less time with others at post-test than at pre-test. However,

scores on this subscale were particularly low across both groups at pre-test indicating that participants initially had few difficulties in this area. Thus, it may be that completing the pre-test resulted in all participants being more aware of this issue at post-test. This effect is referred to as beta change and can result in changes occurring in the opposite direction to that which was hypothesised as a result of participants re-calibrating their responses (Bartholomew, 2002). Participant scores across the other PED subscales were higher than the *Lack of Time With Others* subscale at pre-test, indicating that participants may have already been aware of the issues that the other subscales addressed.

As suitable self-report measures have not been available previously and no previous studies have investigated the impact of sibling intervention programs on the perceived effect of disability, these results cannot be compared with previous studies. However, there are a number of possible explanations for the lack of support for the hypotheses. First, floor effects may have occurred, as participant scores indicated few difficulties at pre-test. It may be that the program is not intensive enough or the program may be ineffective. Low participant numbers resulted in low power, thus making it difficult for any significant changes to be observed. As the PED measure is new and has not been tested on a number of populations, it may not be sensitive enough to change.

The present study hypothesised that participants' perception of their family adjustment would increase significantly. This outcome was included because through siblings' participating in the program, indirectly their families' resources and supports as a whole may have also have been influenced. However, there were no significant differences in participants' reporting of their family adjustment at post-test compared to pre-test. Participants' scores on the family adjustment measure were well below the clinical level, with only two teenagers reporting scores in the clinical range at pre-test. Hence, floor effects may have limited any impact of the intervention. As the comparison group did not complete this measure it is not clear whether stable levels of family functioning are to be expected for such a sample of adolescents.

It is important to note that whilst quantitative evidence was not found to support this hypothesis, just over 60% of the intervention group teenagers reported an improved attitude towards their sibling or their sibling's disability at post-test, a factor that is likely to be associated with better family functioning. Forty-five percent of parents also reported that they observed an increase in siblings' tolerance towards their brother or sister with a disability after the intervention. These qualitative results indicate outcomes that relate specifically to the functioning of families in the context of having a child with a disability, and less to general family functioning. Hence, the Family Adjustment Device measure may not have captured these specific changes in the present study. These results are in line with those found in

Lobato's (1985) study. Five of the six participants in her study displayed an increase in positive verbalisations about their family after a workshop program.

The last hypothesis proposed that participant's self-esteem would significantly improve from pre- to post-test. This hypothesis was not supported, as participants' reports of self-concept and other areas of self-perception, such as their relations with peers and their parents, and emotional stability remained stable over time. The teenagers in the present study showed limited variability in scores across pre-test on the self description subscales, particularly on the General Self subscale where participant scores were generally very high, creating a ceiling effect, with little possibility of change. Again the lack of a comparison group precludes an analysis of this result in relation to adolescent siblings of child with disabilities who did not participate in such a program.

Phillips (1999), Evans et al. (2001) and McLinden et al. (1991) have measured the adjustment of siblings after a group program. The present results are similar to that found by McLinden et al. (1991) who investigated self-concept and sibling behaviour problems as outcomes. McLinden et al. found that participant scores on these outcome measures were within the normal range at pre-test and no significant differences emerged at post-test between the six participants who received the intervention and five participants that did not. However, these results are in contrast to results

found by Phillips and Evans et al.. Phillips reported that the level of depression and anxiety symptoms as well as stress levels (sibling-related) of participants in their intervention groups had significantly decreased from pre to post-test compared to the comparison group. Phillips also found participants' self-esteem and social support levels increased post-intervention. Phillips' study differs from the current study in that the sample size was larger ( $N = 180$ ) providing more power to find effects. In addition, the sample comprised economically disadvantaged participants who faced multiple challenges in their lives. Interestingly, despite the strength of Phillips' study, there were no significant intervention effects found for an increase in family functioning or siblings' relationship.

The lack of support for the hypotheses is inconsistent with Evans and colleagues (2001) study. They found quantitative evidence for improved family relations reported by siblings participating in their support group, using the Family Relations Test (Bene & Anthony, 1985). This measure indicated that siblings' involvement with each other had increased after the intervention. In addition, these researchers found that participant's self-esteem, as rated on the Culture Free Self Esteem Test (Battle, 1981), increased from pre- to post-test. However, no comparison group was used in the Evans et al. study and thus these improvements may not be attributable to the intervention.

The results reported by Phillips (1999) were based on a 15-week program while that of Evans et al. (2001) were based a 3-day workshop with a 6-week follow-up program. As results from longer programs, such as these have demonstrated improvements on quantitative measures, it could be argued that the current intervention was too short or not intensive enough to result in differences across the outcome measures. The relatively short time period of the intervention may have meant that there was not a sufficient time for siblings to process the information and issues raised in the groups and thus put in place some of the strategies introduced through the intervention. Given that the Double ABCX model (McCubbin & Patterson, 1983) predicts positive adaptation when resources are high and the perception of the stressors are positive, if participants did not have sufficient time to utilise the support of new members of their network, to use the range of coping strategies covered in their daily lives or to put their overall situation into perspective after completing the program, a change in adjustment scores would not occur.

Furthermore, the Double ABCX model (McCubbin & Patterson, 1983), which suggests that if one's resources, such as social supports and coping skills are increased, along with a more adaptive perception of the stressor, adjustment is likely to increase. As participant scores on the adjustment measures were high at pre-test, this may have affected the potential improvement of participant scores at post-test. Certainly, while scores on the adjustment measures at pre-test indicated that participants in the present study had high

overall adjustment, Phillips' (1999) sample were at the other end of the scale, being chosen due to being disadvantaged. While Phillips had a large sample size ( $N = 180$ ), the present study had small participant numbers resulting in low power. Similarly, while there were only 18 participants in Evans et al.'s (2001) sample it comprised siblings who were identified by their parents as requiring support. This may account for the differences between the results of the present study compared to that of Phillips and Evans et al..

## **9.2 Social Validity of the Intervention**

Facilitators reported implementation successes across each group and found the only implementation difficulties were keeping the group on task and dealing with disruptive behaviour. The manuals were found to be useful and clear. The overall structure of the program was found to be good, with group cohesion increasing with lower numbers.

All of the parents reported that their children enjoyed attending the groups and reports from participants supported this. Most parents indicated that they would like their child to participate in another sibling program at some stage (69.2%). This result is similar to that of Heiney et al. (1990) who found the majority siblings attending their groups were satisfied with the sessions, glad they participated and interested in attending future group sessions.

There were three main areas of change reported by participants. Siblings overall reported a change in attitude towards their brother or sister with disability, a change in attitude towards disability in general and an increased ability to deal with problems that occur. Similarly, many siblings in Heiney et al.'s (1990) groups reported that they felt they had learnt varied ways to cope with problems.

The majority of parents noticed changes in their child since attending the group sessions, with two main areas of change emerging - increased tolerance and communication skills. The majority (91.67%) of parents in this study noticed changes in their child since attending the groups. This is in line with parent feedback in past studies. For example, in McLinden's (1991) study, 30% of mothers reported that siblings' behaviour towards their sibling was more positive as a result of attending the group sessions. All of the parents who completed evaluations in the Evans et al. (2001) program reported that their children enjoyed attending the group sessions and half of them reported they had observed a change in the way their child related to their brother or sister since attending the group sessions. Correspondingly, almost half of parents (46.2%) of participants in the present study reported an increase in sibling's tolerance towards their brother or sister with an intellectual disability and many siblings (46.2%) themselves reported an improvement in their attitude towards their sibling as a result of attending the groups. These results also support the belief of Flynn and Meakin (1989)

who argue that support groups for siblings can improve tolerance towards children with special needs.

Participants were asked at the end of each group session the activities that they most and least enjoyed. A range of activities was listed after every session, indicating a diversity of enjoyment. Participants were also asked about the group session that they most enjoyed. The most popular session listed by participants (30.8%) was the "Sharing My Story" activity. The "Exploring Differences and Disabilities", "Coping Skills 1" and "Finding Meaning" activities were each rated most enjoyable by two participants (15.4%). This result supports that of past studies such as Dyson's (1998) study where over a third of participants reported that they most enjoyed learning about their brother or sister's disability and the best way to interact with them. Many siblings in Dyson's study, when asked about what they would have liked the group sessions to include, suggested learning more about their brother or sister who had a disability. Some participants in Dyson's study also expressed a wish to meet a person who had grown up with a brother or sister with a disability or wished that they could learn more about other special needs. When participants in the present study were asked a similar question about what else they would like included in the program, few tangible responses were provided – the most common response "nothing". Two comments were made about additional food that could have been provided and two comments were made regarding participants wishing there was more time in the group sessions.

Thus the pilot intervention was found to be easy to implement and had high client satisfaction. Hence, this hypothesis was supported.

### **9.3 Limitations of the Present Research**

Difficulty reaching adequate participant numbers resulted in a lack of a comparison group for all outcome variables thus limiting the overall findings. Participant numbers were small. While many parents wanted their child to attend the group program, transport to the groups was a barrier. The groups were located in a central area, however some families had to travel as far as one hour to attend. For those with limited support networks, inability to find a carer for their child with a disability meant they were unable to take their other child/ren to the group sessions.

The samples for Study 1 and 2 were different in terms that may have influenced the results of the intervention. The majority of parents in Study 1 reported that their child with an intellectual disability required “support in all areas”. However, the majority of parents of children in the Study 2 intervention group reported that their child with a disability required “limited support in two or more areas of daily living”. Given that adjustment levels of siblings are influenced by the severity of their brother or sisters’ disability (eg. Minnes, 1988), the sample of siblings that attended the intervention groups may have presented higher adjustment levels than those in the wider population. Severity of a child disability contributes to family resources (b)

on the ABCX model (Wikler, 1986) and the lack of variability across participants may have contributed to the lack of support for the hypotheses.

A small sample size resulted in low power to detect significant changes across time. As the aim of the study was to have sufficient power to detect a medium effect at least 33 participants per group was needed (Aron & Aron, 1994). In addition, siblings from a wide age-range (12-17 years) were included in the groups, resulting in the facilitators having to consider the cognitive development of each group member when presenting activities. This may have attributed to the lack of significant findings. Due to the fact that the entire population of teenage siblings of children with disabilities was in Western Australia was identified and contacted regarding the various stages of this research project, it was not possible to recruit more participants to the intervention study or to organise the groups into smaller age groups to tailor the intervention according to their cognitive development.

The present intervention was run over six weeks and participants were asked to complete the measures on the first group and on the last group. While this decision was made to limit the amount of time required for participants, it may not have allowed sufficient time for skill development or generalisation of skills. In addition, bias may have occurred with participants completing the measures in a socially desirable manner in order to please the group facilitators.

This relatively short time period may have meant that there was not a sufficient time for siblings to process the information and issues raised in the groups and thus put in place some of the strategies introduced through the intervention. Researchers who have evaluated programs of similar length have also failed to observe positive improvements in participants through quantitative measures (e.g. McLinden, Miler & Deprey, 1991). In contrast, results from longer programs, such as those evaluated by Phillips (1999) and Evan, Jones & Mansell (2001) have demonstrated improvements on quantitative measures. While the results reported by Phillips were based on a 15 week program that of Evans et al. were from a three day workshop followed by a six-week program. This suggests that if the groups were run over a longer period and participants completed the outcome measures outside of the intervention times, this may have allowed quantitative improvements to be observed.

Last, every effort was made to make the intervention as time effective as possible as many families sacrifice a lot to attend the group sessions (e.g.. sporting activities etc.). However, in doing so, times for some of the sessions were underestimated and thus all components of the intervention were not implemented. Overall, an average of 80% of the intervention content was implemented, with a range of 50% - 100% of each group session. This limitation meant that participants did not get the full dose of the intervention. For example, the coping strategies were only able to be discussed, not practiced, and sufficient time was not able to be spent

exploring siblings' perceptions of their situation. As this is an important aspect of the Double ABCX model (McCubbin & Patterson, 1983), this is likely to have influenced the lack of quantitative support for the proposed hypotheses.

#### **9.4 Implications for Future Research**

The current research indicated that a weekly 1.5 hour 6-session program for teenage siblings of children with disabilities was not sufficient to improve the perceived effect of disability on the family and social lives of siblings, despite the fact that participants and families were satisfied with the program and its outcomes. This result could be related to the lack of effectiveness of the program content, the lack of power to detect effects because of the small sample size, the relative health and well-being of the final intervention sample, or the lack of sensitivity of the outcome measures. Future research on intervention programs to reduce the perceived effect of disability on siblings requires larger sample sizes and randomised comparison groups to fully test primary outcomes relating to the impact of disability, and secondary outcomes such as adjustment, self perceptions and family functioning. Other researchers have used measures of psychological and behavioural wellbeing as outcome measures, and have found significant effects (e.g., Phillips, 1999). Hence additional measures of psychological and behavioural adjustment may be more sensitive to the impact of such a program.

Evaluation of the qualitative and implementation data suggests that the intervention required more time to fully cover all the content, and allow participants to engage in active practice of the strategies presented. As the Double ABCX model (McCubbin & Patterson, 1983) predicts positive adaptation when resources are high and the perception of the stressors are positive, researchers should ensure that the length of future programs is sufficient to allow participants to be able to put the presented strategies in place.

Future research should also aim to include participation from a wider range of siblings by assisting those that may have difficulty attending. It is often the case that children who are having difficulty adjusting are unable to access such programs. Reasons for this include children not being linked in with a service that offers such a program, lack of transport, high care-taking responsibilities, and in some cases, due to the emotional problems experienced by parents/caregivers. Having participants meet on an informal basis before the formal group sessions start may allow those children who are shy and a bit apprehensive to familiarise themselves with the other group members and address any other concerns they may have about the program. Thus, these barriers to attendance should be addressed by future research and practice.

If possible, siblings of a closer age-range, for example 12-14 years, 15-17 years should also be grouped together. The facilitators in the present study

noted that this would allow the groups to be more tailored to the cognitive development of members. Other researchers, such as McLinden et al. (1991), have noted that the effectiveness of such groups may be related to participants' age.

Future research should ensure that evaluations of the final intervention are conducted prior to the first group and after the last group, with researchers blind to the participant's group membership. While a follow-up of participants was not in the scope of the present project, future research should also aim to follow up participants 3-6 months after the intervention to investigate maintenance of the effects.

Given that the Double ABCX model (McCubbin & Patterson, 1983) suggested that levels of social support influences family adjustment, it is important that future research includes siblings from a range of adjustment levels. The Double ABCX model (McCubbin & Patterson) predicts positive adjustments if the family's resources and support networks are high, along with a positive perception of the stressor. While there was a lack of quantitative support for the hypotheses proposed, qualitative feedback from participants and parents indicated that positive changes occurred over the group sessions. The inclusion of a parent component in future sibling programs may increase parental support. This may then have an overall impact on siblings perception of their family situation.

## 9.5 Implications for Service Delivery

Of the limited number of services for families who have a child with a disability, even fewer are located in country areas. The possibility of completing a handbook and accessing support online from a counsellor or from other siblings in an Internet discussion group may be a successful option for some. Given the growing use of the Internet, particularly with teenagers, this option would allow a growing number of siblings to access the program. It would not require direct contact with other siblings, however, anonymity through discussion groups over the Internet might prove just as successful for some. Telephone group counselling is another avenue for program delivery. These options may be more desirable for teenagers who are too shy or apprehensive, or those who have difficulty with transport.

Many parents had the opportunity of meeting through the group program, and were able to share their stories with others for the first time. This arrangement would provide opportunity for simultaneous parent sessions, thus supporting Lobato and Kaos' (2002) suggestion of the importance of using parents as a way of supporting siblings through a group program.

The present project drew information from Study 1 along with previous research to deliver a program based on the Double ABCX model (McCubbin & Patterson, 1983). Participant and facilitator feedback demonstrated that the

program was socially valid. However, the outcomes of the research are as yet unclear and need to be tested with larger more representative sample.

## **9.6 Summary**

The quantitative analyses did not support the efficacy of the intervention in terms of reducing the perceived impact of disability on siblings, enhancing their self-descriptions, or promoting family functioning. Both intervention and comparison groups reported less time with others at post-intervention compared to pre-intervention. Despite this, qualitative data showed that siblings enjoyed attending the group sessions and noted benefits in attending the group sessions. Siblings reported an improved attitude towards their sibling with an intellectual disability and disability in general, and increased problem-solving skills, while parents observed an increase in siblings' tolerance and communication skills. The facilitators reported that the program was easy to deliver, but more time was needed to cover all the content in depth. Modification of the program and further evaluation of its effects are required to determine if it is an effective intervention for siblings of children with intellectual disabilities.

## *Chapter 10: Summary and Conclusions*

This research project investigated the effect of disability of siblings of children with intellectual disabilities. It involved two studies. The aims of the first study were, first to develop a measure of the perceived effect of disability on teenage siblings, and second to assess the psychometric properties of this measure. The second study involved the development of an intervention to reduce the impact of disability on siblings of children with intellectual disabilities. The aims of this second study were, first to develop the intervention to address the needs of teenage siblings, and second to evaluate the efficacy and social validity of this intervention.

In total, 145 eligible families participated in Study 1 and 26 participants in Study 2, 13 in the intervention and 13 in the comparison group. These families all had a child with an intellectual disability below the age of 18 years and a sibling between the ages of 12 and 17, and all lived in Western Australia. This chapter will summarise the results of both studies and then discuss the overall implications and limitations of the research. Suggestions for future research will then be presented, followed by overall conclusions of the research.

## 10.1 The Perceived Effect of Disability Measure

The objectives of Study 1 were to identify the needs of siblings in past literature and investigate the current needs of teenage siblings through quantitative and qualitative means. This allowed for the development of a self-report measure of the Perceived Effect of Disability for teenage siblings of children with an intellectual disability. The factor structure and reliability of the underlying the measure were determined.

At the start of this research project no published measures were available to assess the effects of disability on siblings using self-report formats.

However, the literature in this area indicated a need for a self-report measure for siblings to report on their particular concerns. Hence, a measure was developed and refined through quantitative and qualitative methodologies. The development of the measure occurred in three stages.

Past literature and previously available measures of parent perceptions of siblings' difficulties served as the basis for the initial item pool. Content analysis indicated that these items represented two issues, the impact on family life and the impact on social life. One hundred and fifty potential items were initially identified and a sample of teenage siblings rated the importance of the items and issues covered in order to validate them and reduce the potential item pool. Focus groups were then run with another sample of siblings to ensure that all pertinent issues were included, to further reduce the item pool, and to enhance the clarity and suitability of items for this age group. This process resulted in a 123-item questionnaire with two

parts, the impact on family life, which included 12 subscales, and the impact on social life, which included 11 subscales. The last stage of Study 1 involved determining the measure's psychometric properties, internal consistency, test-retest reliability, content and construct validity, and conducting exploratory factor analyses to determine the measure's underlying factor structure.

The final measure included 40 items and included two parts, the impact on family life and the impact on social life for siblings. The questionnaire comprised four factors: two relating to family life *Positive Influence of Disability*, *Family Differences*, and two relating to impact on social life *Worry About What Others Think* and *Lack of Time With Others*. These factors had high internal consistency and test-retest reliability over a six-week period.

As no other reliable and valid self-report measure of the effects of disability on siblings has been identified, this measure will provide opportunities for further research to access the perceptions of siblings without the bias of using secondary sources such as parents. In the process this measure has provided up-to-date information on how siblings in our community believe having a brother or sister with a disability has affected their lives. This new measure will allow future research to more accurately explore the variables that influence the effect of disability on siblings. The PED measure can be used to evaluate the sibling needs in communities and to provide evidence for the needs for increased services. Another potential use of the PED

measure is as an outcome measure for interventions for families of children with disabilities. With this in mind an intervention was developed to assist teenage siblings to deal with the impact of their brother or sister's disability.

During the course of this research, there has been an increased interest by parents in Western Australia concerning the impact of disability on siblings and what the supports and services are needed. Thus, the development of this measure and program is timely.

## **10.2 The Sibling Intervention**

The objectives of Study 2 were to develop an evidence-based intervention to assist the positive adjustment of teenage siblings of children with an intellectual disability and to assess the effectiveness of this intervention with qualitative and quantitative data.

The final intervention (see Volume 2) consists of eight 2-hour group sessions (two informal sessions and six formal sessions) covering the following topics:

- 1.) Sharing My Story
- 2.) Exploring Differences and Understanding Disabilities
- 3.) Exploring and Communicating Feelings
- 4.) Coping Skills 1

## 5.) Coping Skills 2

## 6.) Finding Meaning

This final program incorporated the aspects of the Double ABCX model (McCubbin & Patterson, 1983) by targeting siblings' resources and supports, along with aiming to change siblings' view of their situation. The strategies included in the program were also based on literature searches relating to the impact of disability, and published and unpublished previous interventions for siblings. It is believed that through siblings' participating in the program, indirectly their families' resources and supports as a whole may have also have been influenced.

The outcomes of the intervention were as follows: participants' perception of the *Positive Influence of Disability* on their lives will increase while participants' perception of *Family Differences*, *Worry About What Others Think* and *Lack of Time With Others* will decrease from pre to post-test and; participants' family adjustment and self esteem will increase from post-test. These outcomes were investigated in Study 2. Evaluation of the intervention using a matched comparison group and pre- to post assessment of outcomes did not support the efficacy of the group program. However, qualitative data showed that participants and their families had noticed positive changes in siblings since completing the intervention indicating the social validity of the intervention. Siblings who participated had high pre-test adjustment levels according to the measures, which allowed for little improvement to be

observed at post-test. Investigation of the sample characteristics of Study 2 participants indicated that siblings with lower adjustment levels that could benefit the most from the program were those that were unable to access the program. Thus, overcoming the barriers for these siblings to attend should be an important aim for future research or practice.

### **10.3 Limitations**

Not obtaining a sufficient sample size is a common difficulty for applied research in general. Compounding this difficulty is the type of population one is researching. Families, particularly siblings of children with an intellectual disability, are a difficult population to research, as disability organisations don't typically collect information about other family members, and identification of the targeted population is difficult and time consuming.

In the current research, selectivity of participants occurred on a number of levels. First, participants were all volunteers, hence, the teenagers and/or parents of teenagers participating were those who were interested in the effects of disability on siblings and supported research in this area. Second, the education levels of parents/caregivers of participants in both studies were higher than that of the national average reported by the Australian Bureau of Statistics (2002). There are a number of reasons for this difference. Parents who are more confident, articulate, and are able to better express themselves may be more likely to want their children to

participate in such research. Similarly, those who have been to university may be less intimidated by university research projects and therefore may be more comfortable with their children participating in such a study.

Next, more than one child from some families were included in the studies. While the number of overlap was low (for example, there were 80 children from 71 families participating in Phase 3, Study 1), some researchers (eg. Lobato, 1983) argue that including more than one child from a family may skew the overall results. Similarly, some children had very young siblings with a disability (eg. 4 months old), which may have influenced their ability to recognise the full ranges of the effects of their sibling's disability on their lives. However, the exclusion of such participants would have made the task of obtaining a sufficient number of participants almost impossible. Future research should however aim for a larger and wider sample of participants to avoid these limitations.

#### **10.4 Future Research**

Future research is needed in relation to "The Perceived Effect of Disability" measure and the sibling intervention program. The construct validity of the Perceived Effect of Disability measure should be investigated using confirmatory factor analysis with data from at least 200 participants. In addition, data from both older and younger siblings could be assessed. If the measure's four-factor structure is confirmed, then the measure can be

used with more confidence, in obtaining child self-reports, as part of routine family assessments or to evaluate the effectiveness of existing services.

Future research should use a randomised controlled trial design with an adequate follow-up period to investigate the effects of the sibling intervention. Evaluation of the efficacy of the intervention with a larger sample of participants is needed to have sufficient power to detect effects (Aron & Aron, 1994). Participant recruitment should aim to incorporate families from disability organisations as well as accessing 'hidden' families who are receiving no services. Hopefully, this will assist with gaining a sample of siblings with a range of adjustment levels to increase the generalisability of the results.

In addition, research should target children who are having difficulty in coping with the effects of their sibling's disability, as such children are at greater risk for maladjustment. If results of such research prove promising, this program could then be incorporated into regular service delivery.

In addition, the intervention should be run over eight weeks with pre and post-test measures collected one week before the intervention starts and one week after the conclusion, resulting in a ten week time period between the two measures. A 3-6 month follow-up should also occur to determine if outcomes are maintained. The results of an efficacy study can then be used

to determine if the program is suitable for use within younger siblings or other disability groups.

Future research and practice needs to consider how best to help siblings attend groups and as such consider issues such as care-giving responsibilities, transport and the provision of alternate formats (day workshops etc.). Siblings of different age groups should also be further consulted about what services they would like to enhance the accessibility and client satisfaction. Some may prefer to access such a program online or receive telephone counselling.

### **10.5 Conclusions**

Quantitative and qualitative data provided evidence for the reliability and validity of the Perceived Effect of Disability measure for teenage siblings of children with an intellectual disability. The measure was found to be internally consistent with high stability across a six-week period. Four factors were derived through exploratory factor analysis, and the content and face validity were confirmed through a process of consensus expert and consumer review.

The measure can be used to highlight areas of teenage sibling needs, or to identify the specific concerns of an individual or community group. This information can then be used to develop strategies to address these needs. The measure can also be used to evaluate the effectiveness of interventions.

An intervention consisting of a six-week program for teenage siblings of children with an intellectual disability was developed. The program combined key components from past research and previous interventions with elements from the Double ABCX model developed by McCubbin and Patterson (1983). The intervention provides a solid program from which further research can be conducted.

Qualitative data from participants, their parents, as well as the facilitators, indicated that the intervention was socially acceptable. There were no significant improvements in siblings' adjustment as measured by the Perceived Effect of Disability, family functioning or self-description measures. However, low participant numbers, reduced power, and floor and ceiling effects across the outcome variables limited the chances of observing improvements in outcome measures.

It is hoped that both the measure and intervention developed through this research may result in more evidence-based supports and services for teenage siblings of children with an intellectual disability in Australia. The information gained through this research project is timely. Sibling issues have been an emerging concern in Australia over the last 2-3 years (Guilfoile, 2004; Strohm, 2004). Both families and service providers are asking "What are the effects on -siblings today?" and "How can we best support them?" Many parents and service providers are keen to support siblings, however, they are unsure where to start and how to obtain assistance. Without

answering the first question, it's almost impossible to address the second. It is hoped that this research has provided answers to both questions by providing a better understanding of what it is like for this unique group of children and how we can best support them.

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Appendix A  
Sources Used to Develop Item Pool

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Source Types

Title

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Appendix B1  
Invitation Letters Stage 1, Study 2

[Date]

Mr and Mrs [surname]  
[street name]  
[suburb]  
[state] [postcode]

Dear

**Re: The "Sibs and Us" Project**

I am writing to invite you to take part in a research project which is looking at the effects of disability on brothers and sisters. To date there has been little research in this important area. This research project is concerned with teenagers views on what it's like to have a brother or sister with an intellectual disability. The research project is titled "Sibs and Us" and is being conducted by Monique Nesa, a Doctoral student from Curtin University of Technology.

We understand that you have a child between the ages of 12-17, which is within the age range of the project, and we would like to include him/her in Stage 1 of the project. This will involve them filling out the enclosed questionnaire which should take only 10-15 minutes to complete. The questionnaire includes a list of questions which relate to the experiences of brothers and sisters of children with special needs. Parents are only asked to fill in a short demographic questionnaire. If you require more questionnaires, please contact us on one of the numbers below.

We have enclosed an information sheet, which we hope, will answer most of your questions about the study. However, if you have any further queries do not hesitate to call Monique Nesa on 9266-3446 at Curtin University of Technology or Mairead McCoy at Disability Services Commission on 9426-9310. If we are not available, please leave a message and we will get back to you as soon as possible.

Thank you very much for your time- we hope to hear from you soon!

Yours Sincerely,

Disability Services Commission

## ***Information Sheet 1 for Brothers and Sisters***

*Thank you for your interest in the "Sibs and Us" project! Below are some of the answers to questions you may have about this project.*

### **What is this project about?**

This project is really interested in teenagers views on what it is like for them to have a brother or sister with an intellectual disability.

### **Why should I participate in it?**

You will be able to express **your** views on what its like so that we can help others. We think it's really important to find out how you feel so that we can let parents know more about what it's really like for the other brothers and sisters. To thank you for your time, those who participate will be put into a draw to win one of six movie prizes! The movie prizes will include movie tickets for you and four friends.

Details are at the end of the questionnaire.

### **Who else is participating in the study?**

*Older* brothers and sisters between the ages of 12-17 years will be invited to participate in the project. Participation in this study is entirely voluntary, which means that you are not required to participate (although we hope you do!) and if you wish to withdraw from the project after you have completed the questionnaire, you may do so at any time. Also, your participation in this study will have no effect on your family's relationship with the Disability Service Commission or any other organisation or agency.

### **Are my answers private?**

Yes. Your answers are completely confidential, which means only the researchers at Curtin University will see them and they will not show them to anyone. If you fill in the entry form to win a movie prize, that will be torn off the so your name will not be recorded on the questionnaire. Make sure once you have completed the questionnaire that you **seal it in the attached envelope** and give it to your mum/dad or guardian.

### **What do I have to do?**

Enclosed in this blue package is a questionnaire with an envelope attached to it (and some minties!). Once you have read through the instructions please complete all of questions and fill out the entry form at the end to go in the draw to win a movie prize. Once you have finished the questionnaire please seal it in the attached envelope and give it to your mum/dad or guardian so that they can send it to the researchers at Curtin University.

### **What if I have any questions?**

If you have any questions, ask your mum/dad or guardian. If they can't help you, you can call the researcher, Monique Nesa on (08) 9266 3446 at Curtin University.

## ***Information Sheet 1 for Parents***

*Thank you for your interest in the "Sibs and Us" project. Below are some of the answers to questions you may have about this project.*

### **Who is conducting the research?**

The research project is being conducted by Monique Nesa as part of a Doctor of Philosophy research project in the School of Psychology at Curtin University of Technology, under the supervision of Professor David Hay, Dr Clare Roberts and Mairead McCoy.

### **What is the aim of this study?**

Teenagers views on what it is like to have a brother or sister with an intellectual disability are really important. This stage of the project is interested in developing a questionnaire on the effect of disability on siblings. Therefore, siblings will be asked the importance of various issues that they may encounter. The research aims to provide information for families to help their sons or daughters who are siblings of a child with an intellectual disability. The information will also be useful for professionals who may otherwise be unaware of the effects disability can have on a sibling, and in future research looking into siblings of children with an intellectual disability.

### **Who will benefit from this research?**

Teenage siblings will be able to express their views on what its like to have a brother or sister with an intellectual disability. Through participating, teenagers will contribute to our understanding of the effects of disability on healthy siblings. This information will be used to develop programs for siblings addressing the various needs they deem important to them. This information will also be useful for parents to better understand the feelings of their other children.

Families will be sent a summary of the overall results of the research project at its completion if they indicate their interest (at the end of the demographic form). Teenagers who participate will also go into a draw to win one of six movie passes each consisting of five movie tickets.

### **Who is participating in the study?**

Families who have a child with an intellectual disability and at least one *older* sibling between the ages of 12-17 years, and are receiving services from the Disability Services Commission will be invited to take part in the study. Information will be collected from the teenage siblings, whilst parents are only asked to answer the short demographic questionnaire and give consent for their teenager to participate. Participation in this study is entirely voluntary, and if you wish to withdraw from the study, you may do so at

## Appendix B3 (Continued)

### Information Letters for Parents of Participants Stage 1, Study 2

any time. Also, your participation in this study will have no effect on your family's relationship with the Disability Service Commission or any other organisation or agency.

#### **How do we participate?**

Enclosed is this white package for parents/guardians and a blue package for teenage siblings. Participation for parents only involves you filling out the enclosed "consent form" and the short demographic form and putting them in the reply-paid envelope. Teenage siblings are asked to complete the blue questionnaire and then seal it in the attached plain envelope. Once these have been completed, teenagers are asked to give you their envelope, so that you can seal it along with your consent form and demographic form in the reply-paid envelope, and send it to us here at Curtin University.

#### **Are we assured of confidentiality?**

Yes. You and your teenager's participation in this study are completely confidential. Any identifying information collected will be kept separate from information recorded on the questionnaire, and therefore, no names or information will be able to be traced back to your family. All completed questionnaires will only be viewed by the researcher and associated supervisors and when not in use, will be kept in a locked file. Any findings of the present study that are published will be done so in a manner that does not allow for the identification of any participant or family member.

#### **Who do I contact if I have any further questions?**

Further information can be obtained from Monique Nesa on (08) 9266 3446, Professor David Hay on (08) 9266 7025 or Mairead McCoy (Disability Services Commission) on (08) 9426 9310. Alternatively, if you would like to talk to someone who is not directly involved in the present study, you can contact Dr. Lyndall Steed (Ethics Committee) on (08) 9266 7182. Your call is welcome.

#### **How do we know we've remembered everything?**

Just use the checklist below!

#### **TEENAGER**

- Completed the questionnaire
- Sealed the questionnaire in the envelope
- Handed mum/dad/guardian the envelope

#### **PARENT**

- Completed the consent form and demographic form
- Put them along with the sealed questionnaire, in the reply-paid envelope
- Posted them all to Curtin University!

Appendix B4  
Reminder Letters Stage 1, Study 2

[Date]

Mr and Mrs [surname]  
[street name]  
[suburb]  
[state] [postcode]

Dear

**Re: The "Sibs and Us" Project**

We understand that families have been busy in the lead up to Christmas so we are re-contacting families for another opportunity to participate in the above project. The project is looking at the effects of disability on brothers and sisters of children with an intellectual disability and is being conducted by Monique Nesa, a Doctoral student in Psychology from Curtin University of Technology.

The project is aimed at older brothers and sisters between the ages of 12 and 17 years. Participation only involves the sibling completing the enclosed questionnaire, which should take approximately 10-15 minutes to complete, and one parent/guardian completing the short demographic questionnaire and returning it in the enclosed envelope by the **25<sup>th</sup> of January**.

We have enclosed an information sheet, which we hope, will answer most of your questions about the study. However, if you have any further queries do not hesitate to call Monique Nesa on 9266-3446 at Curtin University of Technology or Mairead McCoy at Disability Services Commission on 9426-9310. If we are not available, please leave a message and we will get back to you as soon as possible.

Thank you very much for your time- we hope to hear from you soon!

Sincerely,

Mairead McCoy  
Principal Clinical Psychologist  
Disability Services Commission

## ***SIBLINGS QUESTIONNAIRE***

Please enjoy the minties while you are filling out this questionnaire!  
This questionnaire is about the feelings and experiences of being a brother or sister of a child with special needs. The questions are based on things that brothers and sisters have said about what it is like for them. There are 2 parts to the questionnaire. Part 1 includes questions about your feelings and experiences in your family life. Part 2 includes questions about your feelings and experiences in your social life.

This questionnaire lists the feelings experiences of brothers and sisters into sections. What we want you to do is think about the question in each section and put the answers below it in rank order of how true they are for you, with 1 being really true for you and the last number being the least true for you. See the example on page 2.

Sometimes none of the answers may seem true to you and sometimes all of them will be true for you. If this is so, we want you to think hard and try and put them in order of how true they are for you.

Sometimes the answers won't apply to you at all. For example if you don't go to the same school as your brother/sister with a disability, the answer "*Looking after your brother or sister at school*" won't apply to you. In this case please put a line through the answer.

This is not a test, so there are no right or wrong answers, only you can honestly tell us about the feelings and experiences of having a brother or sister with a disability.

Your answers are confidential, which means that we will not tell anyone about them, so please make sure you seal the questionnaire in the attached envelope when you finish and give it to your mum, dad or guardian so they can send it back to us.

*Thank you for your time!*

# PART 1- FAMILY LIFE

ID \_\_\_\_\_

**EXAMPLE.** *What do I do in my spare time?*

*Please rank items in this section from 1-3, in order of how true they are for you.*

\_\_\_\_\_ *I really like going to the movies*

\_\_\_\_\_ *I spend a lot of time reading*

\_\_\_\_\_ *I go to the beach often*

*If the statement "I really like going to movies" is really true for you, you would put a number 1 next to it as follows:*

1 *"I really like going to the movies"*

*If you believe it is not true at all or least true for you, please place it last on the list. As this example has 3 answers, you would put a number 3 next to it:*

3 *"I really like going to the movies"*

If it's *a bit true* for you, but not as true as the other answers, you would put it as a two. Let's get started!

\_\_\_\_\_ **A.** *What has my family learnt from my brother/sisters disability?*

*Please rank items in this section from 1-11, in order of how true they are for you. 1 = really true for you, 11 = least true or not true at all true for you .*

\_\_\_\_\_ *Living with ..... has taught me a lot about people that are different.*

\_\_\_\_\_ *My family has learnt a lot about life from ..... 's disability.*

\_\_\_\_\_ *I have learned to be more assertive since ..... was born.*

\_\_\_\_\_ *I appreciate my own health more because of ..... 's disability.*

\_\_\_\_\_ *I have learned to speak out on behalf of my family.*

\_\_\_\_\_ *Having ..... in our family has helped me to learn how to cope with stress and worry.*

\_\_\_\_\_ *I am able to appreciate the simple things in life.*

\_\_\_\_\_ *..... has taught me so much about what life really means.*

\_\_\_\_\_ *I think having ..... in our family has made me a more patient person.*

\_\_\_\_\_ *I think having ..... in our family has helped me understand more about other people's feelings.*

\_\_\_\_\_ *Having ..... in our family has made me a more honest person.*

Appendix B5 (Continued)  
Version 1 of the Measure Stage 1, Study 1

\_\_\_\_\_ **B. What are the good things about my brother/sister?**

Please rank items in this section from 1-5, in order of how true they are for you.

- \_\_\_\_\_ I like doing things with .....
- \_\_\_\_\_ I admire .....
- \_\_\_\_\_ It's fun to do things with .....
- \_\_\_\_\_ I like having ..... in my family.
- \_\_\_\_\_ My relationship with ..... is better than my friends relationship with their brother/sister/s.

\_\_\_\_\_ **C. How close is my family?**

Please rank items in this section from 1-3, in order of how true they are for you.

- \_\_\_\_\_ My family is closer since ..... was born.
- \_\_\_\_\_ Our experience of ..... 's disability has brought our whole family together.
- \_\_\_\_\_ We do more as a family, I think, because of the way ..... is.

\_\_\_\_\_ **D. What are the good things about my family?**

Please rank items in this section from 1-6, in order of how true they are for you.

- \_\_\_\_\_ My parents accept everyone in the family equally.
- \_\_\_\_\_ My family gets to meet lots of people through the agencies where ..... gets cared for.
- \_\_\_\_\_ I have an important role in my family.
- \_\_\_\_\_ ..... makes our family life more fun!
- \_\_\_\_\_ My parents don't mind if their children aren't perfect.
- \_\_\_\_\_ My family life is more interesting because of .....

\_\_\_\_\_ **E. What is my family's communication like ?**

Please rank items in this section from 1-4, in order of how true they are for you.

- \_\_\_\_\_ I wish my family would talk more openly about difficulties with .....
- \_\_\_\_\_ I don't discuss my feelings towards ..... to protect my parents.
- \_\_\_\_\_ My family doesn't talk much about what will happen to ..... when s/he grows up.
- \_\_\_\_\_ I wish my family would talk more openly about ..... 's condition.

Appendix B5 (Continued)

Version 1 of the Measure Stage 1, Study 1

**\_\_\_\_\_ F. How much responsibility do I have?**

Please rank items in this section from 1-7, in order of how true they are for you.

- \_\_\_\_\_ I think having a brother or sister with an intellectual disability makes my parents expect more of me.
- \_\_\_\_\_ I have more responsibilities in my family than my friends do.
- \_\_\_\_\_ If I didn't help out, my mum would have too much work taking care of .....
- \_\_\_\_\_ If I didn't help out, my dad would have too much work taking care of .....
- \_\_\_\_\_ I wish I didn't have to take care of ..... so much of the time
- \_\_\_\_\_ I have more jobs to do around the house than my friends do.
- \_\_\_\_\_ I spend a lot of my free time taking care of .....

**\_\_\_\_\_ G. How do others treat me compared to my brother/sister?**

Please rank items in this section from 1-7, in order of how true they are for you.

- \_\_\_\_\_ My parents treat me differently from .....
- \_\_\_\_\_ Sometimes I think my parents love ..... more than me.
- \_\_\_\_\_ I feel angry when ..... gets away with things I'm not allowed to do.
- \_\_\_\_\_ Sometimes I think of ..... as lucky because s/he gets special treatment.
- \_\_\_\_\_ I get annoyed that ..... 's small accomplishments usually get lots of attention from my parents.
- \_\_\_\_\_ I get told off more than ..... even if it's not my fault.
- \_\_\_\_\_ My parents have to spend so much money on the needs of ...., that there isn't much money left over for my needs/wants.

**\_\_\_\_\_ H. How much attention do I receive from my parents?**

Please rank items in this section from 1-4, in order of how true they are for you.

- \_\_\_\_\_ My mum has to spend so much time caring for ..... that she doesn't have enough time for me.
- \_\_\_\_\_ My dad has to spend so much time caring for ..... that he doesn't have enough time for me.
- \_\_\_\_\_ It upsets me that I don't get as much attention as .....
- \_\_\_\_\_ My accomplishments are usually overlooked by my parents.

**\_\_\_\_\_ I. What is my relationship like with my brother/sister?**

Please rank items in this section from 1-8, in order of how true they are for you.

- \_\_\_\_\_ I argue with ..... more than I think other brothers and sisters do.
- \_\_\_\_\_ I try to avoid being around ..... too much.
- \_\_\_\_\_ My relationship with ..... is worse than my friends relationship with their

Appendix B5 (Continued)

Version 1 of the Measure Stage 1, Study 1

brother and or sisters.

- \_\_\_\_\_ I don't feel as if I can stand up to ..... because s/he has a disability.
- \_\_\_\_\_ ..... is more aggressive towards me than my friend's brothers/sisters are to them.
- \_\_\_\_\_ I can't have a normal relationship with ..... no matter how hard I try.
- \_\_\_\_\_ I can't relate to ..... like a proper brother/sister.
- \_\_\_\_\_ There are things I would like to talk about with ....., but I cant because of the way s/he is.

\_\_\_\_\_ **J. What is my brother/sisters behaviour like?**

Please rank items in this section from 1-5, in order of how true they are for you.

- \_\_\_\_\_ Our mealtimes are sometimes disrupted by ..... 's behaviour.
- \_\_\_\_\_ ..... usually bugs me while I'm doing homework.
- \_\_\_\_\_ I get upset because ..... ruins many of my things.
- \_\_\_\_\_ I don't get much time to myself because ..... interrupts me.
- \_\_\_\_\_ My family and I are always tired because ..... often wakes up in the middle of the night.

\_\_\_\_\_ **K. How do I feel compared to others?**

Please rank items in this section from 1-6, in order of how true they are for you.

- \_\_\_\_\_ Life in my family is really different from life in other families.
- \_\_\_\_\_ We don't get to go out much and do things that other families do.
- \_\_\_\_\_ People look at my family differently when they know about ..... 's disability.
- \_\_\_\_\_ I wish people could understand our family more.
- \_\_\_\_\_ Things are harder in my family because of ..... 's disability.
- \_\_\_\_\_ My family misses out on opportunities that other families get to do such as going on holidays together.

\_\_\_\_\_ **L. What concerns do I have?**

Please rank items in this section from 1-8, in order of how true they are for you.

- \_\_\_\_\_ I am really worried about what will happen to ..... when he/she grows up.
- \_\_\_\_\_ I worry about what will happen to ..... if anything happens to me.
- \_\_\_\_\_ I wish I could go to the same school as .....
- \_\_\_\_\_ I wish ..... could go to a school closer to our home.
- \_\_\_\_\_ I worry about ..... when s/he has to go to the doctors.
- \_\_\_\_\_ I worry that ..... will have to live with me when parents are too old to

Appendix B5 (Continued)

Version 1 of the Measure Stage 1, Study 1

look after him/her.

- Because of ..... 's needs, it's harder for me to think about moving out of home and starting my own life.
- I think that ..... will influence my future decisions such as where I live, who I live with etc.
- Sometimes I worry that when I have a family of my own, I may have a child with a disability.

**\_\_\_\_\_ M. How has my brother/sister's disability impacted on my family?**

Please rank items in this section from 1-4, in order of how true they are for you.

- My family is always stressed.
- I think my family feels hard done by.
- Our family can't do things on the "spur of the moment" because of ..... 's needs.
- There is not much freedom for my family.

**\_\_\_\_\_ N. How do I feel?**

Please rank items in this section from 1-7, in order of how true they are for you.

- I feel guilty because I can do things that ..... can't do.
- I am jealous of all the attention that ..... gets.
- I feel like I caused ..... to be the way he/she is.
- I feel guilty when I think bad thoughts about .....
- I feel like it should have been me with the disability instead of .....
- I am worried that I too may get what ..... has.
- I feel guilty that I am healthy and ..... is not.

**THANKYOU! You have reached the end of PART 1.**

*Some of the sections (A-N) above may have seemed more important to you than others. Now go back and put a tick ✓ next to the sections you thought were most important to you and put a cross ✗ next to the sections that seemed irrelevant to you. For those sections where you aren't sure, please leave them blank. For example, if section A is really important to you, you would place a tick next to it as follows:*

A. "What has my family learnt from my brother/sister's disability?"

*If A is not important to you, you would place a cross next to it:*

A. "What has my family learnt from my brother/sister's disability?"

*If you aren't sure, you would leave it blank.*

A. "What has my family learnt from my brother/sister's disability?"

**Please turn the page over for Part 2**

## PART 2- SOCIAL LIFE

### \_\_\_\_\_ A. What opportunities have come out of my brother/sister's condition?

Please rank items in this section from 1-5, in order of how true they are for you. Remember, if it's *really true* for you put it as number 1, if it's *not true* for you, put it as number 5.

- \_\_\_\_\_ People are curious about ..... 's disability and ask me lots of questions.
- \_\_\_\_\_ My teacher knows about ..... and is really understanding.
- \_\_\_\_\_ I have more friends because of .....
- \_\_\_\_\_ People feel that they can talk to me because I am more caring than others.
- \_\_\_\_\_ I get to meet more people because of .....

### \_\_\_\_\_ B. How proud do I feel about my brother/sister?

Please rank items in this section from 1-3, in order of how true they are for you.

- \_\_\_\_\_ I feel proud when I teach ..... something.
- \_\_\_\_\_ I enjoy taking ..... on outings.
- \_\_\_\_\_ I am proud when I am out with my family.

### \_\_\_\_\_ C. What's it like to explain my brother/sister's condition to others?

Please rank items in this section from 1-6, in order of how true they are for you.

- \_\_\_\_\_ I'd rather people didn't know I had a brother/sister with a developmental disability.
- \_\_\_\_\_ I have trouble explaining ..... to my boyfriend/girlfriend/best friend.
- \_\_\_\_\_ I haven't told my teachers about ..... because I'd rather they didn't know.
- \_\_\_\_\_ I am too embarrassed to tell my friends about ..... 's disability.
- \_\_\_\_\_ I don't know how to explain ..... 's disability to my friends.
- \_\_\_\_\_ I make up stories about ..... because I'm too embarrassed to tell the truth.

### \_\_\_\_\_ D. What opportunities do I miss out on?

Please rank items in this section from 1-5, in order of how true they are for you.

- \_\_\_\_\_ I'm not allowed to have friends over as much as others do.
- \_\_\_\_\_ I wish I had more time with my friends.

Appendix B5 (Continued)

Version 1 of the Measure Stage 1, Study 1

- \_\_\_\_\_ I am annoyed that I can't do "normal activities" that others get to do.
- \_\_\_\_\_ I would never bring my girlfriend/boyfriend/best friend home because of.....
- \_\_\_\_\_ I wish I didn't have a brother/sister with a disability, so that I could be more like my friends.

\_\_\_\_\_ **E. How do my friends feel around my brother/sister?**

Please rank items in this section from 1-5, in order of how true they for you.

- \_\_\_\_\_ I think some of my friends feel funny around .....
- \_\_\_\_\_ I think some of my friends feel uncomfortable about ..... 's disability.
- \_\_\_\_\_ Some of my friends act weird around .....
- \_\_\_\_\_ I think some of my friends are scared around .....
- \_\_\_\_\_ Many friends don't come over because of .....

\_\_\_\_\_ **F. How do others treat my brother/sister?**

Please rank items in this section from 1-3, in order of how true they are for you.

- \_\_\_\_\_ People feel too uncomfortable to talk about ..... with me.
- \_\_\_\_\_ Others try to ignore ..... when they are around.
- \_\_\_\_\_ Others try to avoid talking about ..... around me so they don't hurt my feelings.

\_\_\_\_\_ **G. Do I ever get embarrassed?**

Please rank items in this section from 1-4, in order of how true they are for you.

- \_\_\_\_\_ I am embarrassed about ..... 's behaviour when we are in public together.
- \_\_\_\_\_ I wish I could just disappear when ..... does embarrassing things.
- \_\_\_\_\_ I pretend I don't know ..... when he/she does embarrassing things.
- \_\_\_\_\_ ..... does silly things when we are out that make others stare at us.

\_\_\_\_\_ **H. Do I get teased?**

Please rank items in this section from 1-5, in order of how true they are for you.

- \_\_\_\_\_ People tease me about .....
- \_\_\_\_\_ I have to stand up for ..... when others tease him/her.
- \_\_\_\_\_ I protect ..... from others teasing.
- \_\_\_\_\_ I get into fights to protect .....
- \_\_\_\_\_ I get upset when others tease ..... in front of me.

Appendix B5 (Continued)

Version 1 of the Measure Stage 1, Study 1

**I. Do I miss out on things that others get to do?**

Please rank items in this section from 1-10, in order of how true they are for you.

- \_\_\_\_\_ I can't play the sports I want to.
- \_\_\_\_\_ I look after ..... at school.
- \_\_\_\_\_ I wish I could do what my friends do after school.
- \_\_\_\_\_ I wish I didn't have to look after ..... so much.
- \_\_\_\_\_ Checking on ..... at school leaves me with less time to spend with friends.
- \_\_\_\_\_ I don't have much time to spend with friends after school because I have to look after .....
- \_\_\_\_\_ I don't invite friends over because they might be uncomfortable around .....
- \_\_\_\_\_ I feel lonely and isolated from others.
- \_\_\_\_\_ I feel angry that I have less chance to go on outings because of ..... 's needs.
- \_\_\_\_\_ I wish I could have more fun with my friends.

**J. Does my sibling disrupting time with friends**

Please rank items in this section from 1-3, in order of how true they are for you.

- \_\_\_\_\_ At times I don't like the way ..... interferes with my plans.
- \_\_\_\_\_ My parents always want me to include ..... in my plans with friends.
- \_\_\_\_\_ ..... always interferes with my time with my friends at home.

**K. How do others treat me?**

Please rank items in this section from 1-10, in order of how true they are for you.

- \_\_\_\_\_ People act differently when they know I have a brother/sister with special needs.
- \_\_\_\_\_ Adults treat me more grown up than others my age.
- \_\_\_\_\_ I get treated differently from others because of .....
- \_\_\_\_\_ People in the street look at me weirdly when I am out with .....
- \_\_\_\_\_ It hurts me when others treat me differently because of .....
- \_\_\_\_\_ I think others expect more from me because I have a brother/sister with a disability.
- \_\_\_\_\_ I feel like I have to prove myself more because of ..... 's disability.
- \_\_\_\_\_ Others constantly compare me to .....
- \_\_\_\_\_ My teachers treat me differently when they find out I have a brother/sister with special needs.
- \_\_\_\_\_ Others people may think that there is something wrong with me because ..... has a disability.

Appendix B5 (Continued)

Version 1 of the Measure Stage 1, Study 1

**\_\_\_\_\_ L. Do others understand me?**

Please rank items in this section from **1-5**, in order of how true they are for you.

- \_\_\_\_\_ No-one understands what it's like for me.
- \_\_\_\_\_ I feel as if I am the only person in the world in this particular situation.
- \_\_\_\_\_ I worry about what others think when I am with .....
- \_\_\_\_\_ Friend's don't understand what its like to have ..... as my brother/sister.
- \_\_\_\_\_ I often think that others don't understand what its like for me and my family.

**THANKYOU! You have reached the end of PART 2.**

*Some of these sections (A-L) may have seemed more important to you than others. Please put a tick ✓ next to the sections you thought were most important to you and put a cross X next to the sections that seemed irrelevant to you. For those sections that you aren't sure on, please leave them blank. For example, if section A is really important to you, you would place a tick next to it as follows:*

*✓ A. "What opportunities have come out of my brother/sister's condition?"*

*If A is not important to you, you would place a cross next to it as follows:*

*X A. "What opportunities have come out of my brother/sister's condition?"*

*If you aren't sure, you would leave it blank.*

*\_\_\_ A. "What opportunities have come out of my brother/sister's condition?"*

*Are there any issues that we have missed that are important to you?*

---

---

---

Now that you have completed the questionnaire, please seal it in the attached envelope and give it to your parent/guardian.

*Thank you for your time!!!!*

-----  
If you would like to go into the draw to win one of six movies prizes for you and four friends, please put your name and contact details below. This information will be kept separate from your questionnaire.

Name: \_\_\_\_\_ Phone Number: \_\_\_\_\_

Address: \_\_\_\_\_ Postcode: \_\_\_\_\_

## Demographic Questionnaire

1. Date: \_\_\_\_\_ ID \_\_\_\_\_

The following questions are about your teenager who is participating in the present project

2. Date of birth: \_\_\_\_\_

3. Gender: Male/Female \_\_\_\_\_

4. Has your child been diagnosed with any disabilities or health problems?  
Yes/No \_\_\_\_\_

**If yes**, please list below.

Disability \_\_\_\_\_

Health Problem/s \_\_\_\_\_

The following questions are about your child with an intellectual disability who is receiving services from DSC

5. Date of birth \_\_\_\_\_

6. Gender: Male/Female \_\_\_\_\_

7. Please indicate the level of support your child requires  
(tick appropriate box): \_\_\_\_\_

1.  Occasional support in two or more areas of daily living
2.  Limited support in two or more areas of daily living
3.  Support in most areas of daily living
4.  Support in all areas of daily living

8. Does your child have any other disabilities or medical conditions? Yes/No \_\_\_\_\_  
**If yes**, please specify: \_\_\_\_\_

9. Has your child with a disability ever attended the same school as the  
participating child? Yes/No \_\_\_\_\_

**If yes**, please specify the length of time together at same school \_\_\_\_\_ yrs \_\_\_\_\_

Please indicate whether they are currently attending the same  
school? Yes/No \_\_\_\_\_



Appendix C1  
Invitation Letters, Stage 2, Study 1

[street name]  
[suburb]  
[state] [postcode]

Dear

**Re: The "Sibs and Us" Project**

I am writing to invite you to take part in a research project, which is looking at the effects of disability on brothers and sisters. To date there has been little research in this important area. This research project is concerned with teenagers' views on what it's like to have a brother or sister with an intellectual disability. The research project is titled "Sibs and Us" and is being conducted by Monique Nesa, a Doctoral student from the School of Psychology at Curtin University of Technology.

We understand that you may have a child between the ages of 12-17 who is an *older* sibling of a child with an intellectual disability. If so, we would like to invite him/her to take part in a discussion group with other siblings, to talk about what it is like for them being an older sibling of a child with special needs.

We have enclosed an information sheet, which we hope, will answer most of your questions about the study. After you and your child have read through these, please fill in the enclosed form indicating your child's interest to participate. Alternatively you can call Monique Nesa on 9266-3446 at Curtin University of Technology or Mairead McCoy at Disability Services Commission on 9426-9310. If we are not available, please leave a message and we will get back to you as soon as possible.

This is an important and worthwhile project so we hope you able to participate. Thank you for your time, we hope to hear from you soon.

Sincerely,

Mairead McCoy  
Principal Clinical Psychologist  
Disability Services Commission

Appendix C1 (Continued)

Invitation Letters, Stage 2, Study 1

[street name]  
[suburb]  
[state] [postcode]

Dear

Thank you for your ongoing support and participation in the "Stepping Stones" project.

Currently there is another project, which is being run at the university, which may be of interest to you and your family. This research project is concerned with teenagers' views on what it's like to have a brother or sister with an intellectual disability. The project is titled "Sibs and Us" and is being conducted by Monique Nesa, a Doctoral student from the School of Psychology at Curtin University of Technology.

I have enclosed an information sheet, which I hope, will answer most of your questions about the project. Please read the information sheet and I will contact you shortly to answer any additional questions you may have and give you information on how you can participate.

Thank you for your time,

Melinda Jeffs  
Project Co-ordinator  
Stepping Stones Project

Appendix C1 (Continued)  
Invitation Letters, Stage 2, Study 1

Dear Parent,

I am writing to invite you to take part in a research project titled "Sibs and Us" which is being conducted through the School of Psychology at Curtin University. I am looking for children between the ages of 12-17 who are *older* siblings of a child with an intellectual disability to take part in the project. If you have a child between these ages, I would like to invite them to take part in a discussion group to talk about what it is like for them being an older sibling of a child with special needs.

I have enclosed an information sheet, which I hope, will answer most of your questions about the project. After you and your child have read through these, please fill in the enclosed form indicating your child's interest to participate. Alternatively you can call Monique Nesa directly on 9266-3446 at Curtin University of Technology. If I am not available, please leave a message and I will get back to you as soon as possible.

This is an important and worthwhile project so I hope you able to participate. Thank you for your time, I hope to hear from you soon.

Kind Regards,

Monique Nesa  
"Sibs and Us" Project  
Curtin University of Technology



## ***Information Sheet 2 for Families***

*Thank you for your interest in the "Sibs and Us" project.  
Below are some of the answers to questions you may have  
about this study.*

### **Who is conducting the research?**

The study is being conducted by Monique Nesa as part of a Doctor of Philosophy research project in the School of Psychology at Curtin University of Technology, under the supervision of Professor David Hay, Dr Clare Roberts and Mairead McCoy.

### **What is the aim of this study?**

Teenager's views on what it is like to have a brother or sister with an intellectual disability are really important. This research project is concerned with teenagers' views on what it's like to have a brother or sister with an intellectual disability. This part of the research involves siblings discussing what it's like for them being a brother or sister of a child with an intellectual disability. The research aims to provide information for families to better understand their sons or daughters who are siblings of a child with an intellectual disability. The information will also be useful for professionals who may otherwise be unaware of the effects disability can have on a sibling, and in future research.

### **Who will benefit from this research?**

Many siblings of children with an intellectual disability never have the opportunity to discuss their experiences with others in the same situation. Participation in this stage of the study will provide siblings with the opportunity to share their experiences with one another in a safe environment. Similarly, parents will have the opportunity to have a chat over morning or afternoon tea with one another. Also, they will be invited to watch "It's a Long Road" which is a short film portraying the emotional journey of four women raising children with disabilities.

Teenagers will also receive a double movie ticket as a thank you for taking part in the discussion group and parents will receive \$15 reimbursement for mileage costs associated with taking their child to the discussion group.

## Appendix C2 (Continued)

### Information Sheets, Stage 2, Study 1

#### **Who is participating in the study?**

Families who have a child with an intellectual disability and at least one *older* sibling between the ages of 12-17 years, and are receiving services from the Disability Services Commission will be invited to take part in the study. Information will be collected from the siblings, whilst parents are only required to answer a short demographic questionnaire and give consent for their teenager to participate. Participation in this study is entirely voluntary, and if you wish to withdraw from the study, you may do so at any time. Also, your participation in this study will have no effect on your family's relationship with the Disability Service Commission or any other organisation or agency.

#### **How will the information be collected?**

Discussion groups will be run from Curtin University of Technology during the **April/May school holidays** and if necessary, after school hours during May. Siblings will only be required to attend one discussion group, which will run for approximately 1 and 1/2 hours. Siblings will first be introduced to one another, share morning or afternoon tea together and then discuss what it's like for them being a brother or sister of a child with special needs. Discussion groups will be audio taped so that no information is missed. The tapes will be transcribed without identifying information, and then wiped.

During this time parents will be asked to complete a short demographic form, and will be invited to share morning or afternoon tea together and then watch the film "It's a Long Road". Alternatively they may want to explore the various shops and cafes around the university.

#### **Who do I contact if I have any further questions?**

Further information can be obtained from Monique Nesa on (08) 9266 3446, Professor David Hay on (08) 9266 7025 or Mairead McCoy (Disability Services Commission) on (08) 9426 9310. Alternatively, if you would like to talk to someone who is not directly involved in the present study, you can contact Dr. Lyndall Steed (Ethics Committee member) on (08) 9266 7182. Your call is welcome.

#### **How do I get involved?**

Please fill in the enclosed form indicating your interest to participate and send it back in the enclosed envelope. Alternatively you can contact Monique directly on 9266 3446, if she is not available please leave a message with your name, telephone number and the best time for her to call you back.

Monique will then contact everyone interested in participating to give them further information on the groups and find out which time is best for them to attend.

Appendix C3  
Statement of Interest, Stage 2, Study 1

## Statement of Interest

Parent/Guardian's Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Telephone Number: \_\_\_\_\_  
Sibling/s' name, age and gender (Optional): \_\_\_\_\_

Please tick the appropriate box:

YES! My adolescent is interested in participating in a sibling group  
(the researcher will contact you soon to give you further information)

OR

No, my adolescent does not wish to participate in a sibling group

OR

I do not have any children between the ages of 12-17 years who are  
older siblings

*The researcher thanks you for your reply!*

Appendix C4

Confirmation Letters, Stage 2, Study 1

Dear <Name>

Thank you for your interest in attending our next discussion group on:

<Date, time>

At Curtin University of Technology, located in Kent Street in Bentley. I have enclosed a road map to help you find your way to Curtin and a coloured map of the university to help you find your way around. When you arrive the university you may park in any of the car parks free of charge (except the metered carpark), however Staff carpark 29 (found at H 11 on the coloured map) is closest to the building where the group is being held. The group is being held in the Psychology building, which is building 401 (found between G/F 12/13 on your coloured map). Once you arrive at the front of the building please go up the main ramp and we will meet there.

From there siblings will go to the group room where they will have a snack together and discuss what it's like for them being a brother/sister of a child with special needs. The group will run for approximately 1 and  $\frac{1}{2}$  hours. Meanwhile, parents will be asked to sign a consent form for their child to participate and then fill in a short demographic form. This will only take about 5 minutes to complete. Parents (other children in the family are also welcome to come along) will then be invited to share afternoon tea together.

If you need to contact me before the group, you can call me at Curtin on 9266 3446 or 041 1120924. Thank you once again for your interest in this project and I look forward to meeting you at the group on <insert date>!

Kind regards,  
Monique Nesa



# Demographic Questionnaire

1. Date: \_\_\_\_\_ ID \_\_\_\_\_

The following questions are about your teenager who is participating in the present project

2. Date of birth: \_\_\_\_\_

3. Gender: Male/Female \_\_\_\_\_

4. Has your child been diagnosed with any disabilities or health problems?  
Yes/No \_\_\_\_\_

**If yes**, please list below.

Disability \_\_\_\_\_

Health Problem/s \_\_\_\_\_

The following questions are about your child with an intellectual disability who is receiving services from DSC

5. Date of birth \_\_\_\_\_

6. Gender: Male/Female \_\_\_\_\_

7. Please indicate the level of support your child requires  
(tick appropriate box): \_\_\_\_\_

1.  Occasional support in two or more areas of daily living

2.  Limited support in two or more areas of daily living

3.  Support in most areas of daily living

4.  Support in all areas of daily living

8. Does your child have any other disabilities or medical conditions? Yes/No \_\_\_\_\_  
**If yes**, please specify: \_\_\_\_\_

9. Has your child with a disability **ever** attended the same school as the participating child? Yes/No \_\_\_\_\_

**If yes**, please specify the length of time together at same school \_\_\_\_\_ yrs

Please indicate whether they are currently attending the same school? Yes/No \_\_\_\_\_

Appendix C5 (Continued)

Demographic Questionnaire, Stage 2, Study 1

The following questions are about the mother of the child who is participating

10. Date of birth: \_\_\_\_\_

11. Level of education (Please circle number)

1. Year 10 2. Year 11 3. Year 12 4. TAFE 5. University 6. Other \_\_\_\_\_

12. Current (or last) paid occupation \_\_\_\_\_

13. Current marital status (Please circle number)

1. Single 2. Defacto 3. Married 4. Separated 5. Divorced 6. Widowed \_\_\_\_\_

The following questions are about the father of the child who is participating

14. Date of birth: \_\_\_\_\_

15. Level of education (Please circle number)

1. Year 10 2. Year 11 3. Year 12 4. TAFE 5. University 6. Other \_\_\_\_\_

16. Current (or last) paid occupation \_\_\_\_\_

17. Current marital status (Please circle number)

1. Single 2. Defacto 3. Married 4. Separated 5. Divorced 6. Widowed \_\_\_\_\_

The following questions are about your family

18. Is your family receiving assistance from any other agency

(eg. Activ Foundation)? Yes/No \_\_\_\_\_

If yes, please specify: \_\_\_\_\_

19. Nowadays family structure is often more complex (e.g., blended families). If the children in your family are not from the same biological parents, could you please describe your family structure. This information is needed to understand how different family variables may influence answers. It will be kept strictly confidential.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Thank you very much for your time!**

-----  
If you would like to receive feedback on the results of this study, please fill out your details in the space provided. This information will be kept separate from the above.

*My current details are as follows.*

**Name:** \_\_\_\_\_ **Phone Number:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Postcode:** \_\_\_\_\_

Appendix C6  
Parent Consent Form, Stage 2, Study 1



## ***STATEMENT OF CONSENT***

I, \_\_\_\_\_, give permission for my child \_\_\_\_\_ to participate in this research project titled "Sibs and Us" which is being conducted by Monique Nesa for a Doctor of Philosophy in Psychology from Curtin University of Technology.

I understand that the aim of this part of the study is to hold a discussion group to discuss a proposed questionnaire which is concerned with the issues siblings of children with a developmental disability may face. I understand that this will involve my child taking part in a discussion group which lasts approximately 1 and  $\frac{1}{2}$  hours, and will be audio taped to ensure that no information is missed.

I understand that my child's participation in this study is entirely voluntary, and that if my child wishes to withdraw from the study or to leave, they may do so at any time, and that they do not need to give any reasons or explanations for doing so. If they do withdraw from the study I understand that this will have no effect on my family's relationship with the Disability Services Commission or any other organisation or agency.

I understand that all of the information my child gives will be kept confidential to the extent permitted by law, and that the names of all people in the study will be kept confidential. I understand that because of this study there could be violations to my child's privacy. To prevent violations of my child's or to other's privacy all participants have been asked not to talk about any private experiences of themselves or other's that they would consider too personal or revealing. I also understand that in order to respect the privacy of the members of the group my child has been asked not to disclose any personal information that they share during their discussion.

The researcher has offered to answer any questions my child or I may have about the study and what my child is expected to do.

I have read and understood this information and I give permission for my child to take part in the study.

\_\_\_\_\_  
Today's date

\_\_\_\_\_  
Your Signature

Appendix D  
Focus Group Protocols

Pilot Group: Protocol

As participants come in, introduce self, give them a nametag to fill in. Ask them to help themselves to drinks, food and have a seat.

Introduction:

*Facilitator*

"Hi everyone, my name is Monique and this is Simone, we are from the "Sibs and Us project" from Curtin University. But before we tell you more about that and what we are doing today. We would like to get to know you all better. So if we can just go around in a circle and say your name, age and what your favourite food is. (if shy, start with Simone and me).

Once finished: "What do you know about what's happening today" or "What has Kim or Bernadette told you about this group?"

Intro to the "Sibs and Us" project.

Discuss confidentiality and importance of keeping discussion private and not telling anyone outside of group. Ask if it's OK to tape.

Show outline of what we will be doing:

Ask you to tell us what it's like for you.

Generate a list of issues in relation to impact of having a brother or sister with an intellectual disability on family and social life

Break

Go through comments other kids have said about what it is like for them being a brother or sister.

Summary of what's been said

Link to previous session/talk- "The talk you just listened to hopefully started you thinking about this. Bernadette also asked you to write down a few things before the camp. So if you're stuck you can always think of what you wrote there."

Clarify any questions- make it clear it is not compulsory.

Appendix D1 (Continued)

Focus Group Protocols

Part 1

*Facilitator*- "To start off, we really want to know what it is like for you to be a brother or sister of a child with a disability. We want to know about how having a brother or sister with an intellectual disability has effected your family life. It's important to remember that we all have different feelings and experiences and some of you here today will have some that are the same, but often they will be different. That's OK- we want to know about everyone's feelings and experiences, whether they are good or bad. Simone is going to jot down your answers on the board".

*Co-Facilitator to list issues generated on Flipchart and clarifies if unsure.*

*Facilitator to probe-*

"What else?"

"Can you tell me more about that?"

"What do you mean by..."

"What does (unclear word) mean?"

"Can you tell me about a time when that happened?"

*Co-facilitator to feedback list at end –"Anything else to add, anything we missed out?"*

Repeat for SOCIAL LIFE

BREAK 10 mins

Introduction to Part 2

*Facilitator* "OK, that's great. You've told us what it's like for you and the issues that come up. Now what we want to do is to show you a list of some of the things, brothers and sisters have said about what it is like for them. It doesn't include everything, as we don't have time. But we would really like to know what you think of these comments"

The first comment is "I have learnt to speak out on behalf of my family"

What do you think about that comment?

*Facilitator to probe-*

"Can you tell me more about that?"

"What do you mean by..."

"Can you tell me about a time when that happened?"

Appendix D1 (Continued)

Focus Group Protocols

*Co-Facilitator to scribe. Indicate the item number the participants are commenting about at that point.*

Continue through all items.

Conclusion

"Ok that was the last comment we wanted to go through. How are you all feeling?" Reflection of feelings.

"If anyone wants to come and talk to me about some of the things we brought up , I would be more than happy to".

## Appendix D1 (Continued)

### Focus Group Protocols

#### Amended Focus Group Protocol

As participants arrive, introduce self, small talk etc. When all members have arrived, go to group room, give participants a nametag.

#### Introduction:

##### *Co-Facilitator*

"Hi everyone, and welcome to our discussion group. Thank you for taking the time out of your school holidays to attend our discussion group, we really appreciate it. My name is Monique and this is Simone, we are from the "Sibs and Us project" from Curtin University. We really want to find out what it is like for brothers and sisters of children with special needs. We've invited you here today to share your thoughts and feelings on what it's like, as we believed you are the best people to tell us what it's like.

Today we'll be discussing your experiences on what it is like being a brother of a child with special needs. We want to hear about good experiences as well as some more difficult situations. There are no right or wrong answers we just want to know what it is like for you.

Before we begin, there are some things we need to go over. Firstly, we would like to see if it is OK with you all if we tape this discussion so that we don't miss any of your comments. Is that OK with everyone? It's also important that anything we say in here today stays in this room, and you don't discuss it with anyone outside of here. We will have a break half way through and we will finish about \_\_\_\_\_.

Before we get started, I think it would be a good idea to get to know each other better because then it will make talking about your experiences easier. So if we can start off by telling each other about ourselves, I'll start."

#### Introductory game

##### Part 1

*Facilitator*- "To start off, we really want to know what it is like for you to be a brother or sister of a child with a disability. We want to know firstly about how having a brother or sister with an intellectual disability has effected your family life. It's important to remember that we all have different feelings and experiences and some of you here today will have some that are the same, but often they will be different. That's OK- we want to know about everyone's feelings and experiences, whether they are good or bad. Monique is going to jot down your answers on the board".

Appendix D1 (Continued)

Focus Group Protocols

*Co-Facilitator to list issues generated on Flipchart and clarifies if unsure.*

*Facilitator to probe-*

"What else?"

"Can you tell me more about that?"

"What do you mean by..."

"What does (unclear word) mean?"

"Can you tell me about a time when that happened?"

*Co-Facilitator to feedback list at end then ask if "Anything else to add, anything we missed out?"*

REPEAT FOR SOCIAL LIFE

BREAK 10 mins

Introduction to Part 2

*Co-facilitator* "OK, that's great. You've told us what it's like for you and the issues that come up. Now what we want to do is to show you a list of some of the things, teenagers have said about what it is like for them being a brother or sister with special needs. We would really like to know if these comments are relevant or important to you"

The first comment is "I have learnt to speak out on behalf of my family"  
What do you think about that comment?

*Facilitator to scribe. Indicate the item number the participants are commenting about at that point. Continue through all items.*

"Ok that was the last comment we wanted to go through. How are you all feeling?" Reflection of feelings.

"Does anyone have any questions about the project or comments about what we have just talked about?"

"If anyone wants to come and talk to either of us about some of the things we brought up today, we would be more than happy to".

Thank all participants.

Appendix E1  
Invitation Letters, Stage 3, Study 1

[Date]

Mr and Mrs [surname]  
[street name]  
[suburb]  
[state] [postcode]

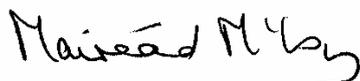
Dear

We think siblings are really special. That is why we are encouraging a new research project, which is concerned with teenagers' views on what it's like to have a brother or sister with an intellectual disability. The research project is titled "Sibs and Us" and is being conducted by Monique Nesa, a Doctoral student from Curtin University of Technology.

We understand that you may have a child between the ages of 12-17 who is a sibling of a child receiving services from the Disability Services Commission and we would like to include him/her in the project. We really hope that you support this new initiative by filling in the enclosed demographic form and by asking your teenager to complete the enclosed questionnaire. By participating in this part of the project families are helping us to ultimately develop sibling groups, which are strongly based on the feelings and experiences of siblings of children with special needs in Western Australia.

We have enclosed an information package for you and your teenager, which we hope, will answer most of your questions about the project. However, if you have any further queries do not hesitate to call Monique Nesa on (08) 9266 3446 at Curtin University of Technology or Mairead McCoy at Disability Services Commission on 9426 9310. If we are not available, please leave a message and we will get back to you as soon as possible.

Kind Regards,



Mairead McCoy  
Disability Services Commission



## ***Information Sheet for Brothers and Sisters***

*Thank you for your interest in the "Sibs and Us" project!  
Below are some of the answers to questions you may have  
about this project.*

### **What is this project about?**

This project is really interested in teenagers' views on what it is like for them to have a brother or sister with an intellectual disability.

### **Why should I participate in it?**

You will be able to express **your** views on what it's like so that we can help others. We think it's really important to find out how you feel so that we can let parents know more about what it's really like for the other brothers and sisters. To thank you for your time, those who participate will be sent a small box of chocolates after they have sent back the enclosed questionnaire and then a second one 1 month later (see below for details). You also have the option of stating your interest in a sibling group, which will be developed in collaboration with the Disability Services Commission of Western Australia. If you are interested in being notified when this commences, please tick the appropriate box on the *Additional Information* form enclosed.

### **Who else is participating in the study?**

Brothers and sisters between the ages of 12-17 years will be invited to participate in the project. Participation in this study is entirely voluntary, which means that you are not required to participate (although we hope you do!) and if you wish to withdraw from the project after you have completed the questionnaire, you may do so at any time. Also, your participation in this study will have no effect on your family's relationship with the Disability Service Commission or any other organisation.

### **Are my answers private?**

Yes. Your answers are completely confidential, which means only the researchers at Curtin University of Technology will see them and they will not show them to anyone. After you have sent back the questionnaire we will remove your name from the front page so your answers remain anonymous.

### **What do I have to do?**

Enclosed in this blue package is a questionnaire with an envelope attached to it (and some treats to eat while you are filling it in!). Once you have read through the instructions please complete all of questions. Once you have finished the questionnaire **please seal it in the attached envelope and give it to your mum/dad or guardian** so that they can send it to the researchers at Curtin University of Technology in Western Australia. You will then be sent **another** copy of the same questionnaire approximately one month later. The reason we need you to complete it a second time is to see if the way teenagers respond are consistent and similar over a given time-frame, however please do not try and remember your answers. You will then be sent a small box of chocolates as a thank you for your participation.



## ***Information Sheet for Parents***

*Thank you for your interest in the "Sibs and Us" project. Below are some of the answers to questions you may have about this project. Please enjoy a cup of tea on us while reading through this sheet and filling in the enclosed forms.*

### **What is this project about?**

This project is really interested in teenagers' views on what it is like for them to have a brother or sister with an intellectual disability.

### **Who will benefit from this research?**

Teenage siblings will be able to express their views on what its like to have a brother or sister with an intellectual disability. Through participating, teenagers will contribute to our understanding of the effects of disability on healthy siblings. This information will be particularly useful for parents to better understand the feelings of their other children. Families will be sent a summary of the overall results of the research project at its completion. All teenagers who participate will be sent a small box of chocolates after completion of both questionnaires.

You also have the option of stating your interest in your teenager participating in a sibling group, which will be developed in collaboration with the Disability Services Commission of Western Australia. If you are interested in being notified when this commences, please tick the appropriate box on the *Additional Information* form enclosed.

### **Who is conducting the research?**

The research project is being conducted by Monique Nesa as part of a Doctor of Philosophy research project in the School of Psychology at Curtin University of Technology, under the supervision of Professor David Hay, Dr Clare Roberts and Ms Mairead McCoy.

### **Who is participating in the study?**

Families who have a child with an intellectual disability and at least one sibling between the ages of 12-17 years, and are receiving services from the Disability Services Commission will be invited to take part in the study. Information will be collected from the teenage siblings, whilst parents are only asked to answer the short demographic questionnaire and give consent for their teenager to participate. Participation in this study is entirely voluntary, and if you wish to withdraw from the study, you may do so at any time. Also, your participation in this study will have no effect on your family's relationship with the Disability Service Commission or any other organisation or agency.

## Appendix E3 (Continued)

### Information Sheets for Parents, Stage 3, Study 1

#### **How do we participate?**

Enclosed is this white package for parents/guardians and a blue package for teenage siblings. Participation for parents only involves you filling out the enclosed demographic questionnaire, which gives us an idea of how representative families that participate are of the general population. Teenage siblings are asked to complete the blue questionnaire and then seal it in the attached plain envelope. Once these have been completed, teenagers are asked to give you their envelope, so that you can seal it along with your demographic questionnaire. Your teenager will then be sent **another** copy of the questionnaire approximately one month later and asked to re-fill it in and send it to us at Curtin University. We ask participants to complete the questionnaire for a second time to see if the way teenagers respond are consistent and similar over a given time frame. If you have more than one child who wishes to participate, please tick the appropriate box on the *Additional Information* form and send it to us at Curtin University.

#### **Are we assured of confidentiality?**

Yes. You and your teenager's participation in this study are completely confidential. Any identifying information collected will be removed from the front page of the questionnaire and therefore, no names or information will be able to be traced back to your family by anyone who is not part of the research project. You are not required to fill in your name on the demographic form. All completed questionnaires and demographic forms will only be viewed by the researcher and associated supervisors and when not in use, will be kept in a locked file. Any findings of the present study that are published will be done so in a manner that does not allow for the identification of any participant or family member.

#### **Who do we contact if I have any further questions?**

Further information can be obtained from Monique Nesa at Curtin University on (08) 9266 3446. If Monique is unavailable, please leave a message and she will contact you as soon as possible to answer your enquiry. Alternatively, you can contact Mairead McCoy from the Disability Services Commission on (08) 9426 9310 or if you would like to talk to someone who is not directly involved in the present study, you can contact Dr. Lyndall Steed (Ethics Committee) on (08) 9266 7182. Your call is welcome.

#### **How do we know we've remembered everything?**

Just use the checklist below!

#### **TEENAGER**

- Complete the questionnaire
- Seal the questionnaire in the envelope
- Hand mum/dad/guardian the envelope

#### **PARENT**

- Complete the *Demographic Form*
- Complete the *Additional Information* form
- Put them along with the sealed questionnaire
- Put them in the reply-paid envelope and post them

Then wait until you hear from us again in one month!!

## ***Additional Information***

Parent/Guardian's Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Sibling/s' name, age and gender (Optional): \_\_\_\_\_

*Please tick the appropriate boxes in section 1 and 2:*

### **1) PARTICIPATION**

My adolescent is interested in participating in this research by completing the questionnaire (enclosed is the completed demographic form and questionnaire)

My adolescent is interested in participating in this research by completing the questionnaire (enclosed is the completed demographic form and questionnaire). My adolescent is also interested in participating in a sibling group at a later stage (the researcher will contact you to give you further information about the sibling group)

I have more than one adolescent interested in participating in this research, please send me \_\_\_\_\_ more questionnaires

My adolescent does not wish to participate in this research

I do not have any children between the ages of 12-17 years who are siblings

### **2) NOTIFICATION OF RESULTS**

I wish to be notified of the results of this research project

I do not wish to be notified of the results of this research project

*The researcher thanks you for your reply!*

Appendix E5

Reminder Letters, Stage 3, Study 1



Dear <Insert Name>

Thank you for your expression of interest in the "Sibs and Us" project. The Christmas and New Year periods are always a busy time, so I am reminding families about the questionnaire packages sent to them just before Christmas. We would like to receive all completed questionnaires by *Friday 17th January 2003*. If you or your family has any questions about the questionnaire please don't hesitate to contact me on 9266 3446.

Thank you once again for your interest in the project and we look forward to receiving your completed questionnaires.

Kind Regards,

Monique Nesa  
"Sibs and Us" Project  
School of Psychology  
Curtin University

Appendix E6

Test-retest Letters, Stage 3, Study 1



Dear <Insert Name>

Thank you for your participation in the "Sibs and Us" project so far! We think it's great that siblings are willing to share their view on what it's like to have a brother or a sister with special needs so we can let parents know what it's like and we can also help other siblings in similar situations.

We have received your completed questionnaire and the demographic form completed by your mum/dad or guardian. As you know, we need participants to fill in the questionnaire *one more time*, 1 month after the first time they filled it in, so we have enclosed another copy of the questionnaire. What we would like you to do is concentrate on how things are like for you right now rather than thinking back to what you put in the last questionnaire. We have put a date on this questionnaire, which is exactly 1 month after when you last filled it in. Please fill the questionnaire in on this day or otherwise the day after. Once you have completed it please send it straight back to us in the enclosed envelope.

To thank you for your time, once you send back this completed questionnaire we will send you a small box of chocolates! If you have any questions please feel free to call me on 92663446. Thanks once again, we look forward to hearing from you soon!

Kind Regards,  
Monique Nesa



# Demographic Form

1. Date: \_\_\_\_\_ ID \_\_\_\_\_

The following questions are about your teenager who is participating in the present project

2. Date of birth: \_\_\_\_\_

3. Gender: Male/Female \_\_\_\_\_

4. Has your child been diagnosed with any disabilities or health problems?  
Yes/No \_\_\_\_\_

**If yes**, please list below.  
Disability \_\_\_\_\_

Health Problem/s \_\_\_\_\_

The following questions are about your child with an intellectual disability who is receiving services from DSC

5. Date of birth \_\_\_\_\_

6. Gender: Male/Female \_\_\_\_\_

7. What diagnosis has your child been given? \_\_\_\_\_

8. Please indicate the level of support your child requires  
(Tick appropriate box): \_\_\_\_\_

- 1.  Occasional support in two or more areas of daily living
- 2.  Limited support in two or more areas of daily living
- 3.  Support in most areas of daily living
- 4.  Support in all areas of daily living

9. Does your child have any other disabilities or medical conditions? Yes/No \_\_\_\_\_  
**If yes**, please specify: \_\_\_\_\_

10. Has your child with a disability **ever** attended the same school as the participating child? Yes/No \_\_\_\_\_  
**If yes**, please specify the length of time together at same school \_\_\_\_\_ yrs \_\_\_\_\_  
Are they are currently attending the same school? Yes/No \_\_\_\_\_

Appendix E7 (Continued)

Demographic Questionnaire, Stage 3, Study 1

The following questions are about the mother of the child who is participating

11. Date of birth: \_\_\_\_\_

12. Level of education (Please circle number)

1. Year 10 2. Year 11 3. Year 12 4. TAFE 5. University 6. Other \_\_\_\_\_

13. Current (or last) paid occupation \_\_\_\_\_

14. Current marital status (Please circle number):

1. Single 2. Defacto 3. Married 4. Separated 5. Divorced 6. Widowed \_\_\_\_\_

The following questions are about the father of the child who is participating

15. Date of birth: \_\_\_\_\_

16. Level of education (Please circle number)

1. Year 10 2. Year 11 3. Year 12 4. TAFE 5. University 6. Other \_\_\_\_\_

17. Current (or last) paid occupation \_\_\_\_\_

18. Current marital status (Please circle number)

1. Single 2. Defacto 3. Married 4. Separated 5. Divorced 6. Widowed \_\_\_\_\_

The following questions are about your family

19. Is your family receiving assistance from any other agency  
(eg. Activ Foundation)? Yes/No \_\_\_\_\_

If yes, please specify: \_\_\_\_\_

20. Has your teenager (who is participating) been involved in any sibling activities  
(eg. camps) or received any assistance/support from an agency? Yes/No \_\_\_\_\_

If yes, please specify support and/or agency: \_\_\_\_\_

21. Please describe anything else that your teenager has been involved in or you have  
provided for them, which may have influenced their experience of having a brother or  
sister with a disability:

\_\_\_\_\_  
\_\_\_\_\_

22. Nowadays family structure is often more complex (e.g., blended families). If the  
children in your family are not from the same biological parents, could you please  
describe your family structure. This information is needed to understand how different  
family variables may influence answers. It will be kept strictly confidential.

\_\_\_\_\_  
\_\_\_\_\_

***Thank you very much for your time!***

Appendix E8  
Copy A Version of Measure, Stage 3, Study 1













Appendix E9  
Copy B Version of Measure, Stage 3, Study 1

















Appendix F1

Follow-up Phone Call Protocols

**Follow-up Phone Calls**  
**STAGE 3 "SIBS AND US" PROJECT**

Goodmorning/Goodafternoon it's \_\_\_\_\_ here calling from the Disability Services Commission. I'm calling about a research project we recently sent you some information about. It's called the "Sibs and Us" project and is concerned with teenagers views on what life is like for them being the sibling of a child with an intellectual disability.

Do you recall receiving this information? (*Please record yes/no on the form.*)

**RECEIVED THE INFORMATION:**

Was it relevant for you? Do you have a teenager between the ages of 12 and 17 who is a sibling of your child who is registered with DSC?

***If Yes***-We're really interested in teenage sibling's views of what life is like for them. What the project involves at this stage asking siblings to complete a short questionnaire. Parents are only asked to complete a short demographic form listing the date of birth of their children etc. Participants are then sent the questionnaire one month later and asked to complete it a second time to see if anything has changed. All siblings' who participate receive a small box of chocolates to thank them. And by participating in this part of the project families are helping us to ultimately develop sibling groups, which are strongly based on the feelings and experiences of siblings of children with special needs in Western Australia. *Ask them if they still have the questionnaire. If they do, ask them we would be very grateful if their family would participate by completing the appropriate forms and returning them in the reply-paid envelope. If no, record address or check if address is correct and that they need a new package- ask how many they need as some families have more than one child in the age-range.*

***If No***- Thank you for taking the time to look through the information. Unfortunately DSC doesn't have information on siblings on our database so we contacted families with a child registered with DSC under the age of 18 years in the hope they had siblings in the age range. Are you still interested in receiving information on the results of the project? *If yes, record on form and record address or check the address DSC has is correct. Let them know we'll send out the information on the results when we have collated them all.*

Appendix F1 (Continued)  
Follow-up Phone Call Protocols

**DID NOT RECEIVE THE INFORMATION:**

Do you have a child between the ages of 12 and 17 who is a sibling of your child who is registered with DSC?

***If Yes-*** What the project involves at this stage is the sibling to complete a short questionnaire which allows them the opportunity to express what life is like for them, and parents are only asked to complete a short demographic form listing the date of birth of their children etc., then participating are sent the questionnaire one month later to see if anything has changed. All participants receive a small box of chocolates to thank them for their participation. By participating in this part of the project families are helping us to ultimately develop sibling groups, which are strongly based on the feelings and experiences of siblings of children with special needs in Western Australia.

***If No-*** Thank you for taking the time to look through the information. Are you still interested in receiving information on the results of the project? *If yes, record on form and record address or check the address DSC has is correct.*

Thank you for your time!

**Other Information**

- If you reach an answering machine, explain the reason why you are calling and tell them that you would be very grateful if they contact the project to let them know if their family can participate.
- If families want a new questionnaire package sent or need more for other siblings, please record this on the sheet along with their address.
- Please record if phone numbers are disconnected or incorrect. A follow-up letter will be sent instead to these families.



## Appendix G1

### Correlation Matrix Resulting from Final Factor Analysis on Part 1 of PED Measure

|               | SMEANP1A1 | SMEANP1A2 | SMEANP1A8 | SMEANP1A9 | SMEANP1A10 | SMEANP1C4 | SMEANP1C6 | SMEANP1C7 | SMEANP1C8 | SMEANP1C9 | SMEANP1C10 | SMEANP1C11 | SMEANP1E1 | SMEANP1E2 | SMEANP1E3 | SMEANP1E4 | SMEANP1H1 | SMEANP1H2 | SMEANP1H4 | SMEANP1J1 | SMEANP1J3 | SMEANP1J5 | SMEANP1J6 |
|---------------|-----------|-----------|-----------|-----------|------------|-----------|-----------|-----------|-----------|-----------|------------|------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| Correlation   | 1.000     | .508      | .383      | .304      | .420       | .236      | .473      | .365      | .432      | .347      | .377       | .276       | .090      | -.136     | -.014     | -.274     | .338      | .250      | .312      | -.140     | -.019     | .010      | -.015     |
|               | .508      | 1.000     | .520      | .226      | .262       | .317      | .316      | .287      | .315      | .360      | .431       | .401       | -.062     | -.195     | -.107     | -.138     | .268      | .293      | .170      | -.123     | -.127     | -.177     | -.091     |
|               | .383      | .520      | 1.000     | .498      | .655       | .548      | .451      | .420      | .587      | .554      | .384       | .324       | .114      | -.085     | -.266     | -.265     | .406      | .359      | .398      | -.005     | -.087     | -.037     | -.164     |
|               | .304      | .226      | .498      | 1.000     | .526       | .396      | .440      | .463      | .382      | .442      | .309       | .289       | -.100     | -.202     | -.331     | -.264     | .286      | .337      | .286      | -.131     | -.117     | -.077     | -.148     |
|               | .420      | .262      | .655      | .526      | 1.000      | .279      | .442      | .422      | .537      | .473      | .294       | .243       | .015      | -.035     | -.255     | -.244     | .293      | .278      | .300      | -.076     | -.024     | .023      | -.239     |
|               | .236      | .317      | .548      | .396      | .279       | 1.000     | .500      | .565      | .479      | .554      | .446       | .261       | .079      | .153      | -.008     | -.056     | .401      | .308      | .395      | .174      | .074      | .277      | .217      |
|               | .473      | .316      | .451      | .440      | .442       | .500      | 1.000     | .444      | .365      | .415      | .409       | .222       | .119      | -.061     | -.275     | -.299     | .340      | .327      | .331      | .009      | .001      | .107      | -.113     |
|               | .365      | .287      | .420      | .463      | .422       | .565      | .444      | 1.000     | .700      | .735      | .587       | .403       | .229      | -.001     | -.195     | -.087     | .591      | .498      | .556      | -.007     | .092      | .197      | .043      |
|               | .432      | .315      | .587      | .382      | .537       | .479      | .365      | .700      | 1.000     | .757      | .599       | .502       | .222      | .016      | -.164     | -.157     | .643      | .579      | .514      | .014      | .041      | .205      | .031      |
|               | .347      | .360      | .554      | .442      | .473       | .554      | .415      | .735      | .757      | 1.000     | .564       | .410       | .092      | -.023     | -.191     | -.146     | .519      | .476      | .485      | -.045     | -.042     | .134      | -.010     |
|               | .377      | .431      | .384      | .309      | .294       | .446      | .409      | .587      | .599      | .564      | 1.000      | .435       | .151      | -.006     | -.148     | -.094     | .586      | .515      | .345      | -.001     | .102      | .092      | .138      |
|               | .276      | .401      | .324      | .289      | .243       | .261      | .222      | .403      | .502      | .410      | .435       | 1.000      | .044      | -.149     | -.158     | -.176     | .334      | .583      | .317      | .044      | -.109     | .067      | .047      |
|               | .090      | -.062     | .114      | -.100     | .015       | .079      | .119      | .229      | .222      | .092      | .151       | .044       | 1.000     | .464      | .300      | .128      | .181      | .200      | .278      | .243      | .353      | .338      | .294      |
|               | -.136     | -.195     | -.085     | -.202     | -.035      | .153      | -.061     | -.001     | .016      | -.023     | -.006      | -.149      | .464      | 1.000     | .431      | .363      | .096      | .068      | .104      | .295      | .405      | .460      | .407      |
|               | -.014     | -.107     | -.266     | -.331     | -.255      | -.008     | -.275     | -.195     | -.164     | -.191     | -.148      | -.158      | .300      | .431      | 1.000     | .450      | -.197     | -.179     | -.066     | .470      | .309      | .360      | .586      |
|               | -.274     | -.138     | -.265     | -.264     | -.244      | -.056     | -.299     | -.087     | -.157     | -.146     | -.094      | -.176      | .128      | .363      | .450      | 1.000     | -.023     | -.038     | -.129     | .251      | .341      | .343      | .345      |
|               | .338      | .268      | .406      | .286      | .293       | .401      | .340      | .591      | .643      | .519      | .586       | .334       | .181      | .096      | -.197     | -.023     | 1.000     | .614      | .464      | .122      | .239      | .188      | .115      |
|               | .250      | .293      | .359      | .337      | .278       | .308      | .327      | .498      | .579      | .476      | .515       | .583       | .200      | .068      | -.179     | -.038     | .614      | 1.000     | .564      | .100      | .161      | .192      | .128      |
|               | .312      | .170      | .398      | .286      | .300       | .395      | .331      | .556      | .514      | .485      | .345       | .317       | .278      | .104      | -.066     | -.129     | .464      | .564      | 1.000     | .179      | .222      | .407      | .166      |
|               | -.140     | -.123     | -.005     | -.131     | -.076      | .174      | .009      | -.007     | .014      | -.045     | -.001      | .044       | .243      | .295      | .470      | .251      | .100      | .179      | 1.000     | .581      | .523      | .569      | .569      |
|               | -.019     | -.127     | -.087     | -.117     | -.024      | .074      | .001      | .092      | .041      | -.042     | .102       | -.109      | .353      | .405      | .309      | .341      | .239      | .161      | .222      | .581      | 1.000     | .494      | .412      |
|               | .010      | -.177     | -.037     | -.077     | .023       | .277      | .107      | .197      | .205      | .134      | .092       | .067       | .338      | .460      | .360      | .343      | .188      | .192      | .407      | .523      | .494      | 1.000     | .595      |
|               | -.015     | -.091     | -.164     | -.148     | -.239      | .217      | -.113     | .043      | .031      | -.010     | -.138      | .047       | .294      | -.113     | .586      | .345      | .115      | .128      | .166      | .569      | .412      | .595      | 1.000     |
| Sig. 1-tailed |           | .000      | .000      | .003      | .000       | .017      | .000      | .000      | .000      | .001      | .000       | .007       | .214      | .114      | .451      | .007      | .001      | .013      | .002      | .108      | .435      | .465      | .448      |
|               | .000      |           | .000      | .022      | .010       | .002      | .005      | .002      | .001      | .000      | .000       | .293       | .041      | .171      | .111      | .008      | .004      | .066      | .139      | .132      | .058      | .211      | .211      |
|               | .000      | .000      | .000      | .000      | .000       | .000      | .000      | .000      | .000      | .000      | .000       | .002       | .157      | .226      | .009      | .009      | .000      | .001      | .000      | .482      | .222      | .373      | .073      |
|               | .003      | .022      | .000      | .000      | .000       | .000      | .000      | .000      | .000      | .000      | .003       | .005       | .189      | .036      | .001      | .009      | .005      | .001      | .005      | .123      | .150      | .249      | .095      |
|               | .000      | .010      | .000      | .000      | .000       | .006      | .000      | .000      | .000      | .000      | .004       | .015       | .449      | .379      | .011      | .015      | .004      | .006      | .003      | .253      | .417      | .419      | .016      |
|               | .017      | .002      | .000      | .000      | .006       | .000      | .000      | .000      | .000      | .000      | .000       | .010       | .242      | .088      | .471      | .310      | .000      | .003      | .000      | .062      | .257      | .006      | .027      |
|               | .000      | .002      | .000      | .000      | .000       | .000      | .000      | .000      | .000      | .000      | .000       | .024       | .147      | .296      | .007      | .004      | .001      | .002      | .001      | .467      | .497      | .173      | .160      |
|               | .000      | .005      | .000      | .000      | .000       | .000      | .000      | .000      | .000      | .000      | .000       | .000       | .021      | .495      | .042      | .221      | .000      | .000      | .000      | .475      | .210      | .040      | .352      |
|               | .000      | .002      | .000      | .000      | .000       | .000      | .000      | .000      | .000      | .000      | .000       | .000       | .024      | .444      | .073      | .082      | .000      | .000      | .000      | .450      | .359      | .034      | .391      |
|               | .001      | .001      | .000      | .000      | .000       | .000      | .000      | .000      | .000      | .000      | .000       | .000       | .209      | .420      | .045      | .099      | .000      | .000      | .000      | .344      | .356      | .117      | .467      |
|               | .000      | .000      | .000      | .003      | .004       | .000      | .000      | .000      | .000      | .000      | .000       | .000       | .091      | .480      | .095      | .205      | .000      | .000      | .001      | .496      | .184      | .209      | .111      |
|               | .007      | .000      | .002      | .005      | .015       | .010      | .024      | .000      | .000      | .000      | .000       | .000       | .348      | .094      | .081      | .059      | .001      | .000      | .002      | .348      | .167      | .276      | .341      |
|               | .214      | .293      | .157      | .189      | .449       | .242      | .147      | .021      | .024      | .209      | .091       | .348       | .000      | .003      | .129      | .054      | .038      | .006      | .015      | .001      | .001      | .004      | .004      |
|               | .114      | .041      | .226      | .036      | .379       | .088      | .296      | .495      | .444      | .420      | .480       | .094       | .000      | .000      | .000      | .000      | .199      | .274      | .180      | .004      | .000      | .000      | .000      |
|               | .451      | .171      | .009      | .001      | .011       | .471      | .007      | .042      | .073      | .045      | .095       | .081       | .003      | .000      | .000      | .040      | .056      | .280      | .000      | .003      | .001      | .000      | .000      |
|               | .007      | .111      | .009      | .009      | .015       | .310      | .004      | .221      | .082      | .099      | .205       | .059       | .129      | .000      | .000      | .419      | .370      | .127      | .012      | .001      | .001      | .001      | .001      |
|               | .001      | .008      | .000      | .005      | .004       | .000      | .001      | .000      | .000      | .000      | .000       | .001       | .054      | .199      | .040      | .419      | .000      | .000      | .000      | .140      | .017      | .048      | .155      |
|               | .013      | .004      | .001      | .001      | .006       | .003      | .002      | .000      | .000      | .000      | .000       | .000       | .038      | .274      | .056      | .370      | .000      | .000      | .000      | .188      | .077      | .044      | .130      |
|               | .002      | .066      | .000      | .005      | .003       | .000      | .001      | .000      | .000      | .000      | .001       | .002       | .006      | .180      | .280      | .012      | .000      | .000      | .000      | .056      | .024      | .000      | .071      |
|               | .108      | .139      | .482      | .123      | .253       | .062      | .467      | .475      | .450      | .344      | .496       | .348       | .015      | .004      | .070      | .027      | .140      | .188      | .056      | .000      | .000      | .000      | .000      |
|               | .435      | .132      | .222      | .150      | .417       | .257      | .497      | .210      | .359      | .356      | .184       | .167       | .001      | .000      | .003      | .001      | .017      | .077      | .024      | .000      | .000      | .000      | .000      |
|               | .465      | .058      | .373      | .249      | .419       | .006      | .173      | .040      | .034      | .117      | .209       | .276       | .001      | .000      | .001      | .001      | .048      | .044      | .000      | .000      | .000      | .000      | .000      |
|               | .448      | .211      | .073      | .095      | .016       | .027      | .160      | .352      | .391      | .467      | .111       | .341       | .004      | .000      | .000      | .001      | .155      | .130      | .071      | .000      | .000      | .000      | .000      |

## Appendix G2

### Correlation Matrix Resulting from Final Factor Analysis on Part 2 of PED Measure

|             |                   | SMEA<br>N  | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N | SMEA<br>N |      |
|-------------|-------------------|------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|------|
| Correlation | SMEAN P2B1        | 1.000      | .652      | .521      | .483      | .170      | .311      | .277      | .391      | .346      | .448      | .430      | .400      | .032      | -.014     | -.005     | .022      | .009      |      |
|             | SMEAN P2B3        | .652       | 1.000     | .494      | .435      | .232      | .343      | .367      | .433      | .451      | .418      | .304      | .339      | .206      | .221      | .272      | .220      | .138      |      |
|             | SMEAN P2B4        | .521       | .494      | 1.000     | .503      | .299      | .393      | .280      | .534      | .358      | .275      | .241      | .255      | .130      | .095      | .279      | .083      | .204      |      |
|             | SMEAN P2B6        | .483       | .435      | .503      | 1.000     | .233      | .321      | .181      | .320      | .397      | .312      | .212      | .486      | .060      | .083      | .110      | .231      | .085      |      |
|             | SMEAN P2D1        | .170       | .232      | .299      | .233      | 1.000     | .667      | .642      | .355      | .399      | .442      | .363      | .248      | .198      | .124      | .180      | .222      | .097      |      |
|             | SMEAN P2D2        | .311       | .343      | .393      | .321      | .667      | 1.000     | .790      | .488      | .402      | .487      | .386      | .347      | .222      | .205      | .248      | .164      | .246      |      |
|             | SMEAN P2D3        | .277       | .367      | .280      | .181      | .642      | .790      | 1.000     | .475      | .448      | .464      | .397      | .303      | .269      | .257      | .151      | .181      | .234      |      |
|             | SMEAN P2E1        | .391       | .433      | .534      | .320      | .355      | .488      | .475      | 1.000     | .681      | .346      | .252      | .245      | .339      | .294      | .392      | .171      | .504      |      |
|             | SMEAN P2E3        | .346       | .451      | .358      | .397      | .399      | .402      | .448      | .681      | 1.000     | .463      | .355      | .383      | .188      | .166      | .368      | .310      | .314      |      |
|             | SMEAN P2F1        | .448       | .418      | .275      | .312      | .442      | .487      | .464      | .346      | .463      | 1.000     | .696      | .678      | .253      | .121      | .156      | .093      | .040      |      |
|             | SMEAN P2F2        | .430       | .304      | .241      | .212      | .363      | .386      | .397      | .252      | .355      | .696      | 1.000     | .634      | .213      | .099      | .084      | .199      | -.004     |      |
|             | SMEAN P2F3        | .400       | .339      | .255      | .486      | .248      | .347      | .303      | .245      | .383      | .678      | .634      | 1.000     | .385      | .069      | .151      | .210      | .072      |      |
|             | SMEAN P2H2        | .032       | .206      | .130      | .060      | .198      | .222      | .269      | .339      | .188      | .253      | .213      | .385      | 1.000     | .504      | .310      | .391      | .326      |      |
|             | SMEAN P2H3        | -.014      | .221      | .095      | .083      | .124      | .205      | .257      | .294      | .166      | .121      | .099      | .069      | .504      | 1.000     | .423      | .413      | .485      |      |
|             | SMEAN P2H5        | -.005      | .272      | .279      | .110      | .180      | .248      | .151      | .392      | .368      | .156      | .084      | .151      | .310      | .423      | 1.000     | .491      | .460      |      |
|             | SMEAN P2H6        | .022       | .220      | .083      | .231      | .222      | .164      | .181      | .171      | .310      | .093      | .199      | .210      | .391      | .413      | .491      | 1.000     | .373      |      |
|             | SMEAN P2H7        | .009       | .138      | .204      | .085      | .097      | .246      | .234      | .504      | .314      | .040      | -.004     | .072      | .326      | .485      | .460      | .373      | 1.000     |      |
|             | Sig. 1-<br>tailed | SMEAN P2B1 | .000      | .000      | .000      | .000      | .065      | .002      | .006      | .000      | .001      | .000      | .000      | .000      | .391      | .451      | .483      | .424      | .469 |
|             |                   | SMEAN P2B3 | .000      | .000      | .000      | .000      | .019      | .001      | .000      | .000      | .000      | .000      | .003      | .001      | .033      | .024      | .007      | .025      | .112 |
|             |                   | SMEAN P2B4 | .000      | .000      | .000      | .000      | .004      | .000      | .006      | .000      | .001      | .007      | .016      | .011      | .125      | .200      | .006      | .232      | .035 |
| SMEAN P2B6  |                   | .000       | .000      | .000      | .000      | .019      | .002      | .054      | .002      | .000      | .002      | .030      | .000      | .298      | .231      | .166      | .020      | .228      |      |
| SMEAN P2D1  |                   | .065       | .019      | .004      | .019      | .000      | .000      | .000      | .001      | .000      | .000      | .000      | .013      | .039      | .136      | .055      | .024      | .196      |      |
| SMEAN P2D2  |                   | .002       | .001      | .000      | .002      | .000      | .000      | .000      | .000      | .000      | .000      | .000      | .001      | .024      | .034      | .013      | .073      | .014      |      |
| SMEAN P2D3  |                   | .006       | .000      | .006      | .054      | .000      | .000      | .000      | .000      | .000      | .000      | .000      | .003      | .008      | .011      | .090      | .054      | .018      |      |
| SMEAN P2E1  |                   | .000       | .000      | .000      | .002      | .001      | .000      | .000      | .000      | .000      | .001      | .012      | .014      | .001      | .004      | .000      | .065      | .000      |      |
| SMEAN P2E3  |                   | .001       | .000      | .001      | .000      | .000      | .000      | .000      | .000      | .000      | .000      | .001      | .000      | .048      | .071      | .000      | .003      | .002      |      |
| SMEAN P2F1  |                   | .000       | .000      | .007      | .002      | .000      | .000      | .000      | .001      | .000      | .000      | .000      | .000      | .012      | .143      | .084      | .207      | .361      |      |
| SMEAN P2F2  |                   | .000       | .003      | .016      | .030      | .000      | .000      | .000      | .012      | .001      | .000      | .000      | .000      | .029      | .191      | .229      | .038      | .488      |      |
| SMEAN P2F3  |                   | .000       | .001      | .011      | .000      | .013      | .001      | .003      | .014      | .000      | .000      | .000      | .000      | .000      | .272      | .091      | .031      | .262      |      |
| SMEAN P2H2  |                   | .391       | .033      | .125      | .298      | .039      | .024      | .008      | .001      | .048      | .012      | .029      | .000      | .000      | .000      | .003      | .000      | .002      |      |
| SMEAN P2H3  |                   | .451       | .024      | .200      | .231      | .136      | .034      | .011      | .004      | .071      | .143      | .191      | .272      | .000      | .000      | .000      | .000      | .000      |      |
| SMEAN P2H5  |                   | .483       | .007      | .006      | .166      | .055      | .013      | .090      | .000      | .000      | .084      | .229      | .091      | .003      | .000      | .000      | .000      | .000      |      |
| SMEAN P2H6  |                   | .424       | .025      | .232      | .020      | .024      | .073      | .054      | .065      | .003      | .207      | .038      | .031      | .000      | .000      | .000      | .000      | .000      |      |
| SMEAN P2H7  |                   | .469       | .112      | .035      | .228      | .196      | .014      | .018      | .000      | .002      | .361      | .488      | .262      | .002      | .000      | .000      | .000      | .000      |      |



## The "Sibs and Us" Project

Do you have difficulty explaining your brother or sister's disability to others? Are there times when you wish you could have a bit of "time-off" from your home life? Do you sometimes feel different from others?

Life as a teenager can be tough at times, and having a brother or sister with a disability can sometimes be an extra challenge. Every teenager who has a brother or sister with a disability has a unique experience so it can be helpful to talk to other siblings about what life is like for them.

That is why we have set up a free six-week program for teenage siblings of children with an intellectual disability.

The groups will be run by Monique Nesa as part of a PhD project at Curtin University. The groups are free of charge and will be conducted in May/June 2003 in Perth and Bunbury with the support of the Disability Services Commission. Drinks and snacks will be provided at each group.

There are many good things that come from meeting other siblings in a group - you will be able to share your stories possibly for the first time; you may be able to help other siblings who are finding their situation particularly challenging or you may be able to pick up some strategies on how to cope with the more difficult times yourself. Also, the groups will be a fun experience!

If you are 12 to 17 years of age and would like to join the sibling groups or know of someone who may be interested, Monique would be happy to hear from you and provide you with more information about them. You can speak to Monique or leave a voice message for her at Curtin University on (08) 9266 3446.



## The "Sibs and Us" Project

Disability does not just impact on the individual, but family members as well. Many researchers have recognized this, and developed services for parents to aid family adjustment. However services for siblings are scarce even though the sibling relationship is typically the longest-lasting relationship in one's life.

Therefore, a project titled "Sibs and Us" has been developed to identify and address current issues for teenage siblings of children with an intellectual disability in our community. The project has been developed by Monique Nesa, a PhD (Psychology) student from Curtin University, in collaboration with the Disability Services Commission.

So far many families in Western Australia have participated in the project by completing questionnaires or by becoming involved in discussion groups. The next stage of the project is the piloting of a group program for teenage siblings of children with special needs. The aim of the groups is to help siblings understand that they are not alone in their situation and to share ideas on how to deal with the various challenges they face in a creative and fun way.

Siblings of children with disabilities often grow up in a stressful environment with many responsibilities, and often don't have the cognitive or coping skills to deal with their experiences. Research has shown that siblings of children with special needs are at an increased rate of developing emotional and behavioural problems, which may lead to greater mental health problems such as the development of anxiety and depression later in life. Furthermore, the impact on siblings occurs throughout their life span and often they are left as the primary carers for their sibling with a disability when their parents are no longer able to care for them.

It is well known that adolescence is typically a very stressful and confusing stage in one's life. Due to this it is believed that adolescence may be particularly challenging time for this unique group of individuals.

## Appendix H2 (Continued)

### Disability Services Staff Advertisements Study 2

Of the research that has looked at how being a sibling of a child with special needs may impact on children, both positive and negative effects have been found. The positive effects include: siblings gaining increased understanding, tolerance, compassion, and appreciation of their own good health and intelligence (Grossman, 1972), and increased sympathy, helpfulness (Jacobs, 1969), and sensitivity (Cleveland & Miller, 1977). The more negative effects that may be observed in some siblings include: feeling shame, anger and guilt (Grossman, 1972), an increased risk of anxiety (Wasserman, 1983), increased caretaking responsibilities (Farber, 1960), the possibility of role crossover (Brody, Stoneman, Davis & Crapps, 1991), dominance (Begun, 1989), deprivation of parental attention, stigmatization (McKeever, 1983) and overall poor individual and maternal adjustment (McHale & Gamble, 1989).

Some siblings also appear to have trouble explaining their brother or sister's disability to their friends. They also tend to have fewer opportunities to participate in out-of-home activities. An obvious factor in this is that extra caregiving responsibilities that many siblings have may result in less contact with friends. Other researchers have found that discomfort on behalf of other children may result in healthy siblings having less contact with friends. This may occur because peers have little understanding about disabilities. As a consequence teasing may occur and this may result in frustration for siblings who want to defend their sibling with a disability however also want to avoid being rejected by their peers. Younger children may also be afraid or feel uneasy around the disabled child and consequently may decide that they do not want to visit their friend who has a brother or sister with a disability (Trevino, 1979). An additional stress for healthy siblings is that their parents often want them to include their sibling with a disability in activities with peers (Trevino).

With the above issues in mind, the Sibs and Us project has developed a 6-week program, which focuses on the positive aspects of being a sibling whilst providing siblings with strategies on how they may deal with the more challenging aspects of being a sibling of a child with special needs.

In general, Kate Strohm (2001, p. 3) advocates that sibling support can:

- Improve the mental health of siblings
- Allow siblings to reach their full potential
- Be a sound investment to service providers
- Improve the quality of life of people with disabilities

Appendix H2 (Continued)  
Disability Services Staff Advertisements Study 2

Furthermore, it is well known that if we increase the resilience and consequently the adjustment of one member of the family, this will ultimately have a positive effect on the whole family. As it is recognized that the roles siblings play in their brother or sisters' health, happiness and community life are vital, Kate Strohm (2001, p. 3) argues that "if children have their feelings validated and needs met, they are much more likely to continue to be involved in their brother or sister's life, and be able to supplement available social services".

Approximately 30 adolescents are required for the piloting of the groups which will be run in June/July 2003 at DSC West Perth and Myaree. If you would like further information on the sibling groups or know of a family who has a sibling between the ages of 12 and 17 years who would like to attend the groups, please contact Monique Nesa at Curtin University on (08) 9266 3446.

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Appendix H2 (Continued)  
Disability Services Staff Advertisements Study 2

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Appendix H3  
Magazine Advertisements Study 2



## The "Sibs and Us" Project

A project titled "Sibs and Us" has been developed by Monique Nesa, a researcher from Curtin University of Technology, to identify and address current issues for teenage siblings of children with an intellectual disability in our community.

So far many families in Western Australia have participated in the project by completing questionnaires or by becoming involved in discussion groups. The next stage of the project is the piloting of a group program for teenage siblings of children with special needs. The aim of the groups is to help siblings understand that they are not alone in their situation and to share ideas on how to deal with the various challenges they face in a creative and fun way.

The groups will be run at various DSC offices in May/June 2003 and siblings will be invited to attend a 1-2 hour group every week for six weeks. Siblings will also be asked to complete a short questionnaire before and after the groups. Refreshments will be provided during the groups.

If you know of any families who have a teenager between the ages of 12 and 17 years who you think may like to attend the 6-week sibling group program or would like further information about the groups, please ask them to contact Monique Nesa at Curtin University on (08) 9266 3446.

## Appendix H4

### Invitation Letter Template, Study 2



## The "Sibs and Us" Project

Dear

I would like to invite you to attend a group program for siblings of children with special needs. We have found that siblings often grow up in a challenging environment with many responsibilities. This challenging environment can provide many positive experiences, as well as sometimes more difficult experiences. Many siblings are more mature than others their age, are more patient and tolerant of others. However, some siblings find it hard to cope with their brother/sister's behaviour at times and may have trouble explaining their brother or sister's disability to others. Other siblings may feel left out or feel frustrated and angry by other people's treatment of their brother or sister. These experiences as well as many more will be explored in the groups and strategies.

Every siblings' experience is different and it is important that siblings meet others to discuss their experiences, the positive and the more challenging ones. Meeting other siblings in a group situation has many benefits- you may be able to help siblings who are finding their situation particularly challenging or you may be able to pick up some strategies on how to cope with the more difficult times and to recognise the positive aspects of your family life.

The groups will be run by Monique Nesa as part of a PhD project at Curtin University of Technology. The groups are free of charge and will be conducted in April/May 2003 from the Bunbury DSC office. The groups will be run for approximately 1 and  $\frac{1}{2}$  hours every week for six weeks. You will be asked to complete a short questionnaire before and after the six-week program. Drinks and snacks will be provided at each group.

If you would like to accept our invitation to join the sibling groups, please call your Local Area Co-ordinator \_\_\_\_\_ on \_\_\_\_\_ or Monique Nesa at Curtin University on (08) 9266 3446.

Thank you for your time and we hope to meet you soon at one of the sibling groups!

Kind Regards,

Monique Nesa  
Sibs and Us Project

Appendix H5  
Personal Invitation Letters, Study 2



## The "Sibs and Us" Project

Dear

Thank you for your involvement in the "Sibs and Us" project so far. You, like many other siblings in Western Australia, have participated in the project so far by completing questionnaires or by becoming involved in a discussion group. The next stage of the project is the piloting of a group program. The aim of the program is for siblings meet others in a similar situation and to share ideas on how to deal with the various challenges you face in a creative and fun way.

I would like to take this opportunity to invite you to attend the program. The program will consist of a 1 and 1/2 hour group every week for six weeks in April/May 2003. Siblings who participate will be asked to complete a short questionnaire before and after the groups. Refreshments at the groups will be also provided.

At the present time we are asking siblings to express their interest and to indicate the most convenient time and place for them attend the groups. I have enclosed a form for you to indicate these preferences and a reply paid envelope for you send back to me at Curtin University of Technology. If you have any questions about the groups, or if you know of any other families who have a teenage sibling (12- 17 yrs) of a child with an intellectual disability who would also like to attend the groups, please contact me (Monique Nesa) at Curtin University on (08) 9266 3446. If I am not available, please leave a message and I will get back to you as soon as possible. Thank you for your time and I look forward to meeting you in the near future!

Kind Regards,  
Monique Nesa

Appendix I1

Preference Form, Sibling Groups



Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ Parent Name: \_\_\_\_\_

Phone No: \_\_\_\_\_ Address: \_\_\_\_\_

Email Address: \_\_\_\_\_ Name/Age Child with Special Needs: \_\_\_\_\_

Where would you prefer to attend the groups?

- DSC West Perth
- DSC Myaree
- DSC Joondalup
- DSC Cannington
- Curtin University of Technology (Bentley)

When would you prefer to attend the groups?

- After school
- Weekends

If you indicated after school, please indicate the time/s and days which are best:

- |                                    |                                      |
|------------------------------------|--------------------------------------|
| <input type="checkbox"/> Monday    | <input type="checkbox"/> 3.30-5pm    |
| <input type="checkbox"/> Tuesday   | <input type="checkbox"/> 4-5.30pm    |
| <input type="checkbox"/> Wednesday | <input type="checkbox"/> 4.30-6pm    |
| <input type="checkbox"/> Thursday  | <input type="checkbox"/> 5-6.30pm    |
| <input type="checkbox"/> Friday    | <input type="checkbox"/> Other _____ |

Appendix I1 (Continued)  
Preference Form, Sibling Groups

If you indicated the weekend, please indicate the time/s and days which are best:

- |                                   |                                      |
|-----------------------------------|--------------------------------------|
| <input type="checkbox"/> Saturday | <input type="checkbox"/> 9.30-11am   |
| <input type="checkbox"/> Sunday   | <input type="checkbox"/> 2-3.30pm    |
|                                   | <input type="checkbox"/> 10-11.30am  |
|                                   | <input type="checkbox"/> 10.30-12pm  |
|                                   | <input type="checkbox"/> 1-2.30pm    |
|                                   | <input type="checkbox"/> 1.30-3pm    |
|                                   | <input type="checkbox"/> Other _____ |

Comments \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Thank you- I will be in contact soon to give you further information!

Appendix 12  
Confirmation Letters, Study 2



Dear <Insert Name>

Thank you for your interest in the sibling groups for the Sibs and Us Project. <Insert Name> is attending the <Insert day> group at <Insert Location> from <Insert Time> for six weeks commencing the <Insert date> until <Insert Date>. The groups will be held at the Disability Services Commission offices at <Insert Address>. I have enclosed a map to help you find your way there. When you arrive you may park in any of the carparks at the front of the building or surrounding areas.

We will meet in the front foyer of the building near reception. From there siblings will go to the group room. Drinks and refreshments will be provided at each group. We ask teenagers involved in the groups to complete this initial questionnaire, complete short forms at the end of each group and another questionnaire booklet at the end of the six weeks in order to monitor the outcome of the groups.

During this time parents (other children in the family are also welcome) are invited to share afternoon tea together. Parents will also be given an information sheet each week outlining what was involved in that week's group. I have enclosed a consent form giving permission for your child to participate and a short demographic form. The demographic form gives us information on whether the families involved in the groups are representative of families in Western Australia in general. These forms will only take about 5 minutes to complete. Please complete these forms and bring them along to the first group.

If you need to contact me before the group, you can call me at Curtin on 9266 3446. Thank you once again for your interest in this project and I look forward to meeting you at your first group on <insert date>!

Kind regards,  
Monique Nesa  
Curtin University of Technology



## ***Information Sheet for Families***

*Thank you for your interest in the "Sibs and Us" project. Below are some of the answers to questions you may have about this project.*

### **Who is conducting the project?**

This research project is being conducted by Monique Nesa as part of a Doctor of Philosophy in the School of Psychology at Curtin University of Technology, under the supervision of Professor David Hay, Dr Clare Roberts and Mairead McCoy.

### **What is the aim of this project?**

Disability does not just impact on the individual, but family members as well. Many researchers and service providers have recognized this, and developed services for parents to aid family adjustment. However services for siblings are scarce even though the sibling relationship is typically the longest-lasting relationship in one's life.

This stage of the project involves the piloting of a 6-week sibling group program. The groups objectives include helping siblings to: understand that they are special and valued in their families and in the community; develop a better understanding of their brother or sister's disability; strengthen communication within their families and friendships; develop active coping skills to manage the various challenges they may face as a sibling of a child with a disability; develop strategies to explain their brother or sisters disability to others; assist siblings in creating a more positive meaning about being a sibling of a child with special needs and most importantly to have fun!

### **What is involved?**

The sibling groups will run for 1 and  $\frac{1}{2}$  hours every week for six weeks. Siblings are required to complete an initial questionnaire and another questionnaire at the completion of the groups in order to monitor the outcome of the groups for participants. Siblings will also be asked to complete a short form at the end of each group asking them to comment on the group such as what activities they most and least enjoyed. Siblings may also be asked permission to allow the facilitators to copy worksheets that they have completed as part of the groups in order to further understand the outcomes of the groups. However any copies made will not contain participant names or any other identifiable information. Parents are only required to answer a short demographic questionnaire and give consent for their teenager to participate.

## Appendix I3 (Continued)

### Information Sheet for Families, Study 2

#### **Who will benefit from this project?**

There are many good things that come from meeting other siblings in a group - siblings will be able to share their stories possibly for the first time; they may be able to help other siblings who are finding their situation particularly challenging or they may be able to pick up some strategies on how to cope with the more difficult times themselves. Also, the groups will be a fun experience for all!

Also, it is envisaged that the information collected during this pilot program may be used to develop a permanent service for siblings in Western Australia.

#### **Who is participating in the project?**

Families who have a child with an intellectual disability between the ages of 12-17 years have been invited to take part in the project through various advertisements and letters sent from Local Area Co-coordinators etc. Participation in this project is entirely voluntary, and if you or your child wishes to withdraw from the project, you may do so at any time. Also, your participation in this project will have no effect on your family's relationship with the Disability Services Commission or any other organisation or agency.

#### **Are we assured of confidentiality?**

Yes. Participation in this project is completely confidential. Only Monique Nesa and the co-facilitator will have access to the information obtained from the groups. Any identifying information collected (such as the consent forms) will be kept separate from information recorded on the demographic forms, and therefore, no names or information will be able to be traced back to your family. It is envisaged that findings from this stage of the project will be published in the future, however information will be published in a manner that does not allow for the identification of any participant or family member.

#### **Who do I contact if I have any further questions?**

Further information about the groups and the overall project can be obtained from Monique Nesa on (08) 9266 3446, Professor David Hay on (08) 9266 7025 or Mairead McCoy (Disability Services Commission) on (08) 9426 9310. Alternatively, if you would like to talk to someone who is not directly involved in the present project, you can contact Dr. Lyndall Steed (Ethics Committee) on (08) 9266 7182. Your call is welcome.

Appendix I4  
Statement of Consent, Study 2



## ***STATEMENT OF CONSENT***

I, \_\_\_\_\_, give permission for my child \_\_\_\_\_ to participate in this research project titled "Sibs and Us" which is being conducted by Monique Nesa for a Doctor of Philosophy in Psychology from Curtin University of Technology.

I understand that the aim of this part of the project is the piloting of a sibling group program. I understand that this will involve my child taking part in a 1 and  $\frac{1}{2}$  hr group once a week for 6 weeks.

I understand that my child's participation in this project is entirely voluntary, and that if my child wishes to withdraw from the program or to leave, they may do so at any time, and that they do not need to give any reasons or explanations for doing so. If they do withdraw from the program I understand that this will have no effect on my family's relationship with the Disability Services Commission or any other organisation or agency.

I understand that all of the information my child gives will be kept confidential to the extent permitted by law, and that the names of all people in the project will be kept confidential. I understand that because of this program there could be violations to my child's privacy. To prevent violations of my child's or to other's privacy all participants will be asked not to talk about any private experiences of themselves or other's that they would consider too personal or revealing. I also understand that in order to respect the privacy of the members of the group my child will be asked not to disclose any personal information that they share during their discussion.

I understand that I have had and continue to have the opportunity to ask questions that either my child or I may have about the project. I have read and understood this information and I give permission for my child to take part in the project.

\_\_\_\_\_  
Today's date

\_\_\_\_\_  
Your Signature

Appendix 15  
Demographic Form, Study 2

## Demographic Form

1. Date: \_\_\_\_\_ ID \_\_\_\_\_

The following questions are about your teenager who is participating in the present project

2. Date of birth: \_\_\_\_\_

3. Gender: Male/Female \_\_\_\_\_

4. Has your child been diagnosed with any disabilities or health problems?  
Yes/No \_\_\_\_\_

**If yes**, please list below. \_\_\_\_\_

Disability \_\_\_\_\_

Health Problem/s \_\_\_\_\_

The following questions are about your child with an intellectual disability who is receiving services from DSC

5. Date of birth \_\_\_\_\_

6. Gender: Male/Female \_\_\_\_\_

7. What diagnosis has your child been given? \_\_\_\_\_

8. Please indicate the level of support your child requires  
(Tick appropriate box): \_\_\_\_\_

1.  Occasional support in two or more areas of daily living

2.  Limited support in two or more areas of daily living

3.  Support in most areas of daily living

4.  Support in all areas of daily living

9. Does your child have any other disabilities or medical conditions? Yes/No \_\_\_\_\_

**If yes**, please specify: \_\_\_\_\_

10. Has your child with a disability **ever** attended the same school as the  
participating child? Yes/No \_\_\_\_\_

**If yes**, please specify the length of time together at same school \_\_\_\_\_ yrs

Are they are currently attending the same school? Yes/No \_\_\_\_\_

Appendix I5 (Continued)  
Demographic Form, Study 2

The following questions are about the mother of the child who is participating

11. Date of birth: \_\_\_\_\_

12. Level of education (Please circle number)  
1. Year 10 2. Year 11 3. Year 12 4. TAFE 5. University 6. Other\_\_\_\_\_

13. Current (or last) paid occupation\_\_\_\_\_

14. Current marital status (Please circle number):  
1. Single 2. Defacto 3. Married 4. Separated 5. Divorced 6. Widowed \_\_\_\_\_

The following questions are about the father of the child who is participating

15. Date of birth: \_\_\_\_\_

16. Level of education (Please circle number)  
1. Year 10 2. Year 11 3. Year 12 4. TAFE 5. University 6. Other\_\_\_\_\_

17. Current (or last) paid occupation\_\_\_\_\_

18. Current marital status (Please circle number)  
1. Single 2. Defacto 3. Married 4. Separated 5. Divorced 6. Widowed \_\_\_\_\_

The following questions are about your family

19. Is your family receiving assistance from any other agency  
(eg. Activ Foundation)? Yes/No \_\_\_\_\_

**If yes**, please specify:\_\_\_\_\_

20. Has your teenager (who is participating) been involved in any sibling activities  
(eg. Sibling groups/ camps) or received any assistance/support from an agency?  
Yes/No \_\_\_\_\_

**If yes**, please specify activity, support and/or agency:\_\_\_\_\_

21. Please describe anything else that your teenager has been involved in or you have  
provided for them, which may have influenced their experience of having a brother or sister  
with a disability:

\_\_\_\_\_

22. Nowadays family structure is often more complex (e.g., blended families). If the children  
in your family are not from the same biological parents, could you please describe your family  
structure. This information is needed to understand how different family variables may  
influence answers. It will be kept strictly confidential.

\_\_\_\_\_

***Thank you very much for your time!***

Appendix J1  
Final Measure, Study 2















Appendix K1  
Facilitator Records- Group Implementation

Facilitator Name: \_\_\_\_\_

Session Number and Date: \_\_\_\_\_

Duration Time: \_\_\_\_\_

Were all activities/discussions completed for this session? Yes/No  
If no, which activities/discussions and why? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Did you make any modifications to this session? Yes/No  
If yes, what were the modifications and why were they made? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Did you feel the overall goals of the session were reached? Yes/No  
If no, what were the barriers? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Were there any difficulties in implementing any of the activities or  
discussions in this session? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Were there any successes in implementing any of the activities or discussions  
in this session? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Which issues raised during the session are important in light of the  
intervention? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Appendix K2

Facilitator Records- Group Attendance and Participation

Please record the attendance and level of participation of each group member for Group No. \_\_\_\_\_

- 4 = Participated in *all* of the Discussion and Activities of the Group
- 3 = Participated in *most* of the Discussion and Activities of the Group
- 2 = Participated in only *some* of the Discussion and Activities of the Group
- 1 = *Did not* participate in any of the Discussion and Activities of the Group

| <u>Name:</u> | <u>Attended:</u> | <u>Level of Participation</u> |   |   |   |
|--------------|------------------|-------------------------------|---|---|---|
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |
| _____        | Yes/No           | 4                             | 3 | 2 | 1 |

Appendix K3

Facilitator Records- Overall Evaluation

Facilitator Name: \_\_\_\_\_

Were all the groups completed? Yes/No

If no, which groups and why? \_\_\_\_\_

\_\_\_\_\_

Did you feel the overall goals of the program were reached? Yes/No

If no, what were the barriers? \_\_\_\_\_

\_\_\_\_\_

Were there any specific difficulties implementing any of the group sessions?

\_\_\_\_\_

\_\_\_\_\_

Were there any specific successes implementing any of the sessions? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Please comment on the structure of the program (eg, number/duration): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Please comment on the usefulness of the Facilitator Manual: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Please comment on the clarity of the Facilitator Manual: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How would you improve the program? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How would you rate the overall success of the program?

4                      2                      3                      1  
Very successful    Quite successful    Slightly successful    Not successful at all

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Appendix K4  
Participant Evaluation of Each Group

Group Number \_\_\_\_\_

What did you learn this session? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How will this help you and/or your sibling? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What activity/discussion did you enjoy the most and why? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What activity/discussion did you enjoy the least and why? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What would you change about it? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Appendix K5  
Overall Participant Evaluation

What is the most important thing you have learnt in the group sessions? \_\_\_\_

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What was your favourite group session and why? \_\_\_\_\_

---

---

---

What was your least favourite group session and why? \_\_\_\_\_

---

---

---

What has changed since you attended the groups? \_\_\_\_\_

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---

---

Appendix K6  
Overall Parent Evaluation

**Please be as open and honest about your answers as possible.  
Thank you for your time and attention.**

**Date of Sibling Group:** \_\_\_\_\_

**Your Child's Name:** \_\_\_\_\_

Has your child talked about what happened at the Sibling group?    Yes    No

Comments: \_\_\_\_\_  
\_\_\_\_\_

Has your child seemed to enjoy the Sibling Groups?    Yes    No

Comments: \_\_\_\_\_  
\_\_\_\_\_

Was there a particular activity that seemed to make a strong impression on  
your child?    Yes    No

Comments: \_\_\_\_\_  
\_\_\_\_\_

Has your child seemed upset/concerned by anything?    Yes    No

Comments: \_\_\_\_\_  
\_\_\_\_\_

Have you noticed any changes in your child since they first started attending  
the group? For eg. a willingness to discuss their feelings, the interaction with  
their brother or sister with special needs, being more positive    Yes    No

Comments: \_\_\_\_\_  
\_\_\_\_\_

Would you like your child to participate in another Sibling group sometime?    Yes    No

Comments: \_\_\_\_\_  
\_\_\_\_\_

Do you have any suggestions about how we could improve the program in  
the future? \_\_\_\_\_  
\_\_\_\_\_

Any other comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**School of Psychology**

**Perceived Effect of Disability on Adolescent Siblings of  
Children with an Intellectual Disability: Development of a  
Measure and Pilot Intervention**

**Monique Nesa**

**VOLUME 2**

**This thesis is presented for the Degree of  
Doctor of Philosophy  
of  
Curtin University of Technology**

**August 2005**

# The Sibs and Us Project



## Facilitator Manual

Written by Monique Nesa

## Acknowledgements

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### Funding:

Disability Services Commission, Metropolitan and Country Services Directorates

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## Program Rationale

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Disability does not just impact on the individual, but family members as well. Many researchers have recognized this, and developed services for parents to aid family adjustment. However services for siblings are scarce even though the sibling relationship is typically the longest-lasting relationship in one's life.

Siblings of children with disabilities may grow up in a stressful environment with many responsibilities, and often don't have the skills to deal with their experiences. Research has shown that siblings of children with special needs experience a range of effects with the impact on siblings occurring throughout their life span. Often they are left as the primary carers for their sibling with a disability when their parents are no longer able to care for them.

It is well known that adolescence is typically a time of transition and personal challenge. Due to this it is believed that adolescence may be particularly challenging time for this unique group of individuals and thus these groups have been developed to focus on the issues that teenage siblings in particular may face.

The research that has looked at how being a sibling of a child with special needs may impact on children, reports both positive and negative effects. The positive effects include: siblings gaining increased understanding, tolerance, compassion, and appreciation of their own good health and intelligence (Grossman, 1972), increased sympathy, helpfulness (Jacobs, 1969), and sensitivity (Cleveland & Miller, 1977). The more negative effects that may be observed in some siblings include: feeling shame, anger and guilt (Grossman, 1972), an increased risk of anxiety (Wasserman, 1983), increased care taking responsibilities (Farber, 1960), the possibility of role crossover (Brody, Stoneman, Davis & Crapps, 1991), dominance (Begun, 1989), deprivation of parental attention, stigmatization (McKeever, 1983) and overall poor individual adjustment (McHale & Gamble, 1989).

In addition, some siblings have trouble explaining their brother or sister's disability to their friends. They may have fewer opportunities to participate in out-of-home activities. An obvious factor in this is that extra care giving responsibilities that many siblings have may result in less contact with friends. Other researchers have found that discomfort on behalf of other children may result in healthy siblings having less contact with friends. This may occur because peers have little understanding about disabilities. As a consequence teasing may occur and this may result in frustration for siblings who want to defend their sibling with a disability however also want to avoid being rejected by their peers. Younger children may also be afraid or feel uneasy around the disabled child and consequently may decide that they do not want to visit their friend who has a brother or sister with a disability

(Trevino, 1979). An additional stress for healthy siblings is that their parents often want them to include their sibling with a disability in activities with peers (Trevino).

With the above issues in mind, the group sessions presented in this manual focus on the positive aspects of being a sibling whilst providing siblings with strategies on how they may deal with the more challenging aspects of being a sibling of a child with special needs.

In general, Kate Strohm (2001, p. 3) advocates that sibling support can:

- Improve the mental health of siblings
- Allow siblings to reach their full potential
- Be a sound investment to service providers
- Improve the quality of life of people with disabilities
- Rebalance societal views

Furthermore, it is well known that if we increase the resilience and consequently the adjustment of one member of the family, this will ultimately have a positive effect on the whole family. As it is recognized that the roles siblings play in their brother or sisters' health, happiness and community life are vital, Kate Strohm (2000, p. 3) argues that "if children have their feelings validated and needs met, they are much more likely to continue to be involved in their brother or sister's life, and be able to supplement available social services".

Therefore, providing siblings with the opportunity to share their ideas, feelings and experiences with other siblings in a safe environment through these group sessions will help their development now and in the future, and will also indirectly help their whole family.

## Overall Aims and Objectives

---

### **Aim**

To develop an evidence-based intervention to assist the positive adjustment of teenage siblings of children with an intellectual disability living in Western Australia.

### **Objectives**

| Group No. | Session Title                          | Objectives                                                                                                                                                                                                                               | Outcomes                                                                                                                                                                                                                                                                                                                       |
|-----------|----------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1         | Sharing My Story                       | <ul style="list-style-type: none"> <li>• Introduce themselves to each other</li> <li>• Siblings share their story with others</li> </ul>                                                                                                 | <ul style="list-style-type: none"> <li>• Siblings develop a rapport with each other</li> <li>• The development of a safe and supportive environment where siblings can share their stories and express their feelings</li> </ul>                                                                                               |
| 2         | Exploring Differences and Disabilities | <ul style="list-style-type: none"> <li>• Discuss the things that they have in common with their sibling and things they don't</li> <li>• Discuss what they know about their sibling's disability</li> <li>• Discuss strengths</li> </ul> | <ul style="list-style-type: none"> <li>• To explore the differences and similarities siblings have with their families and others</li> <li>• To build knowledge and understanding about disabilities</li> <li>• To enhance knowledge about personal strengths and the strengths of their siblings with a disability</li> </ul> |
| 3         | Exploring and Communicating Feelings   | <ul style="list-style-type: none"> <li>• Discuss different types of feelings</li> <li>• Discuss the roles of social support and barriers to accessing it</li> </ul>                                                                      | <ul style="list-style-type: none"> <li>• To enhance awareness of feelings regarding having a brother or sister with a disability</li> <li>• To enhance family communication regarding challenging situations</li> </ul>                                                                                                        |
| 4         | Coping Skills I                        | <ul style="list-style-type: none"> <li>• Present problem-solving steps</li> <li>• Engage in role-plays about difficulties siblings may face in order to practice problem-solving</li> </ul>                                              | <ul style="list-style-type: none"> <li>• To identify and access support when needed</li> <li>• To know and demonstrate problem-solving skills when facing challenging situations where participants may have some control over the outcome</li> </ul>                                                                          |
| 5         | Coping Skills II                       | <ul style="list-style-type: none"> <li>• Discuss and practice a range of coping skills</li> </ul>                                                                                                                                        | <ul style="list-style-type: none"> <li>• To identify and apply coping skills to deal with the more challenging times</li> </ul>                                                                                                                                                                                                |
| 6         | Finding Meaning                        | <ul style="list-style-type: none"> <li>• Reflect on information from past sessions</li> <li>• Rate enjoyment of the groups and what was learnt</li> </ul>                                                                                | <ul style="list-style-type: none"> <li>• Review and reflect on past learning</li> <li>• Integrate past sessions to help participants find meaning in their situation</li> <li>• Evaluate group intervention</li> </ul>                                                                                                         |

## **Informal Group Sessions**

---

Siblings can feel apprehensive or shy about attending a sibling group. This may be because they don't know who the other groups members will be or what they are like, sometimes it is because they are unsure about what the aim of the group is. No matter how much you advertise the groups, this may still be an issue. It often affects participant numbers at the groups, due to some siblings not putting their hand up to attend or changing their minds before attending the first group.

Therefore, it is important to organise an informal gathering before the first sibling group, so siblings can meet others for the first time and talk about what's involved in the group and what they'd like to get out of it. This can be organised as a picnic, pizza day or outing.

Similarly, for those siblings who go on to attend the groups, strong bonds between members often form. As a way of wrapping up all that is covered during the group sessions and reinforcing some of the skills, an outing after the groups is recommended. This allows siblings to spend time with each other in a different setting and often leads to ongoing friendships after the formal group sessions, which can be very supportive for siblings.

In this last meeting, allow group members to swap contact details with others in the group. Send a sheet around for email/mail addresses to be checked and/or recorded.

It's also helpful to take a group photo with a Digital camera and send a copy to each member after the group's completion.

## **Timing of Group Sessions**

---

The groups are designed to be run for 2 hours over 8 weeks. The first meeting should be on an informal basis, for siblings to get to know each other and discuss what the groups will be involved and what they would like to get out of them. The last group should be an informal group to celebrate all that they have achieved over the last few weeks and build upon their friendships with each other to hopefully establish ingoing supports.

Breaks should be between 10-20 minutes half way through the groups to recharge the group. You can also suggest some quick physical games in this time to help those children who may be getting fidgety, to release some energy!

## Transport and Food

---

Families of children with disabilities often have a number of responsibilities and commitments, therefore finding time to take their other children to a sibling group can often be difficult. Therefore, some help with transport to the groups may be required. Some disability organizations are able to help with this, but car pooling is another option. Also consider running the group sessions near public transport.

Having food and beverages at the groups also helps teenagers feel more comfortable and helps give a more casual, informal feel to the groups. You may like to ask your participants what food they most enjoy or ask one or two different group members to bring snacks each week. It is also important to enquire about allergies or special diets before the groups start.

Having a specific time for the food and beverages is required as problems have arisen in the past when food is present from the start of the group. Participants may get distracted by this and it may take attention away from the activities/discussions.

## Managing Disruptive Behaviour

---

Consider the kinds of behaviours you think may disrupt your sibling group sessions before the first group session. Also consider how these behaviours may be addressed. This will ensure potential disruptive behaviour is prevented or successfully dealt with when it arises.

Having a co-facilitator also helps ensure disruptive behaviour is managed well. Have facilitators sit down before the groups and discuss simple behaviour management strategies to put in place. These include, ensuring the group rules are established early and agreed upon by all, ensuring the groups go at an adequate pace to avoid potential boredom leading to misbehaviour, having participants switch places every week to ensure 'clickiness' does not occur or one participant's bad behaviour rubbing off on another.

# Materials

---

- Whiteboard and markers
- Name Tags
- Paper
- Textas
- Ripped up paper/magazines
- Glue
- Highlighters
- Pens
- Jellybabies
- Copies of *Find Someone Like Me.....* for each facilitator (Week 1)
- Copies of the Role-Play Scenarios for each participant (Week 4, Appendix 2)
- Blank Cards for Week 4 and *Our Uniqueness* (Week 6)
- Digital camera

## Supplementary Materials

Many of the activities require participants to record their feelings and/or experiences. Therefore a *"Sibs and Us" Participant Booklet* has been developed to complement this facilitators manual.

It is also important that parents are aware of what their children are learning and discussing in the groups. Therefore *Parent Information Sheets* have been provided in the appendices of this manual. These information sheets may be given to parents by the facilitators at the end of each group or you may prefer the participants to pass on these information sheets to their parents. The parent information sheets are designed to foster discussion between parent and teenager and to encourage open communication between participants and their families. A record sheet to record participant family information is provided in Appendix 5 to allow you to keep track of the participant details such as the name and age of their brother or sister with a disability.

**Week 1:**

# **Sharing My Story**

## Week 1: Sharing My Story

### **Outcomes:**

---

Siblings develop a rapport with each other

The development of a safe and supportive environment where siblings can share their stories and express their feelings

### **Agenda:**

---

Welcome  
Introduction to Group  
My Family  
Who Are We?

### **Materials Needed:**

---

Participant booklets  
Name tags  
Pens  
Textas  
Ripped up paper/Magazines  
Glue  
Scissors  
Copies of "Find Someone Who..." for facilitators  
2 Large sheets of paper

### **1. Welcome (20 mins)**

Have a few tables set up with participant manuals, pens and textas and the correct number of chairs placed around in a circle at the front of the tables. As each participant arrives present them with a blank tag and ask them to design their own nametag.

*Welcome everyone, my name is \_\_\_\_\_ and this is \_\_\_\_\_ and we will be running the sibling groups with you for the next six-weeks. You will find on the table in front of you, a booklet for each of you. If you have a look at your participant booklets you will see we have activities in there. We will be using this booklet at each group to do various activities and also to write down important information and your thoughts and feelings about each group. We also have a few questions we'd like you to answer at the end of each week to see what parts of the group you enjoyed the most. We'll ask you to complete these at the end of each of the group sessions. Take a couple of minutes now to have a quick look through your booklet.*

Give participants a few minutes to look through these.

*Are there any questions about that?*

Address any questions/concerns that arise.

*The groups will go for around two hours and there will be snack breaks scheduled in. The toilets are also located over \_\_\_\_\_. At any time if you feel uncomfortable or you don't want to participant in an activity please let \_\_\_\_\_ or myself know.*

*Before we get started what we'd like to do is help everyone get to know each other. So we'd like you to turn to page 6 of your booklet where you will see an activity called Find Someone Who.... We'd like to spend a few minutes on this now- what you need to do is get the signature of someone with each of these characteristics. You ask anyone including \_\_\_\_\_ and myself. When you're ready you can start getting your signatures.*

**Find Someone Who.....**

Participants turn to page 6 of their participant manuals and facilitators photocopy this activity for themselves and join in. Participants go around the room and get signatures of others who have the various characteristics.



**Find Someone Who.....**

- Has seen Lord of the Rings \_\_\_\_\_
- Loves chocolate \_\_\_\_\_
- Has been to Sydney \_\_\_\_\_
- Watches Big Brother \_\_\_\_\_
- Has been to a concert \_\_\_\_\_
- Has 2 brothers \_\_\_\_\_
- Prefers reading to watching TV \_\_\_\_\_
- Plays video games \_\_\_\_\_
- Can wolf whistle \_\_\_\_\_
- Likes football \_\_\_\_\_
- Can draw well \_\_\_\_\_
- Likes going to the beach \_\_\_\_\_
- Is wearing red \_\_\_\_\_
- Has blue eyes \_\_\_\_\_
- Likes Eminem \_\_\_\_\_
- Plays more than one sport \_\_\_\_\_
- Shares a room \_\_\_\_\_
- Hates broccoli \_\_\_\_\_
- Can roll their tongue \_\_\_\_\_
- Has curly hair \_\_\_\_\_
- Speaks another language \_\_\_\_\_
- Has a part-time job \_\_\_\_\_
- Can pat their head and rub their  
stomach at the same time \_\_\_\_\_

## **2. Introduction to Groups (20 mins)**

### **Introductions**

*How did everyone find that activity? Now that you've met a few people, we'd like you to pair up with someone and introduce yourself to them. We'd like you to tell them your name, favourite hobby and what you'd do if you won a million dollars. After a couple of minutes we'll tell you to swap over and your partner can tell their name, favourite hobby and what they'd do with a million dollars. Then we'll meet back here and you can introduce your partner to the rest of the group and vice versa.*

Participants pair up and one person introduces himself or herself to the other. Facilitators can also join in. After 2-3 minutes one of the facilitators asks everyone to swap and the other pair now introduces themselves. After another 2-3 minutes everyone meets back as a group. Participants are asked to introduce their partner to the rest of the group and tell the group what they remember about their partner.

### **Discussion of Groups**

*Ok, by now you should know a little bit about everyone in the group and realise that everyone here has a brother or sister with a disability. What we'd like to do now is talk a little bit about what we are going to be doing in the groups for the next few weeks and to see what you would like to get out of them. Firstly we'd like to know why you think that you are here and what you would like to like to get out of the group.*

Go around the group and ask each group member what they think they are there and also what they'd like to get out of the groups. Clarify any misinformation siblings may have about why they are there. Write the objectives participants come up with on the whiteboard and discuss as appropriate. Record this list to refer back to at the last group (week 6) to ensure participant's objectives were achieved.

*OK, thanks for letting us know what you would like to get out of these groups. We have also come up with a list of things we would like to cover. The main reason we set up these groups is so that you all can meet other teenagers in a similar situation to yourself and to share your feelings and experiences about what it is like to be a sibling of a child with special needs. We firstly would like everyone to get to know each other and learn a bit about each other's family. Next week we will look at sharing what you know about your brother/sister's disability, and look at the similarities and differences you have with them and others. We would also like to explore your strengths and the strengths of your brother or sister. In later sessions*

*we will also look at what it's like for you being a sibling, look at how to deal with the more challenging situations you may face and look at different types of coping like relaxation and turning to others.*

*We know that you are all the experts here- you all know what it is like to be a sibling of a child with a disability and we think that you are all very special and can learn and share a lot from each other. Of course we will be running the groups and directing the activities, and we aim to provide you with additional support and strategies that you can take away and use in your everyday lives. However the really positive thing here is that you will be able to share information, advice and your experiences with each other.*

*We want to be able to have a supportive group so you all feel comfortable sharing your experiences so we would like to discuss some ways to ensure this happens. Firstly, we ask each of you to not discuss what anyone else says in the group outside of it. We are happy for you to talk to your friends or families about what you do in the groups and what you talk about, but we don't want you to repeat exact things that people say. We will also keep what you say private and not tell anyone unless we feel you need some help. In that case, we'd let your parents know, however talk to you first before we told anyone else what you have told us. Does that make sense to everybody?*

Check that each member of the group understands.

*It would help the group to run smoothly if we listen whilst others are talking- I know sometimes it's hard when you want to say something, but the rule is one person speaks at a time. Also we need to respect others- so no put-downs. Does that make sense to everyone? Is there any other rules anyone wants to have for our groups?*

Discuss any other rules participants suggest and write them on a flip chart to refer to at other times.

### **3. My Family (20 mins)**

#### **Picture of My Family**

*Now that we have gotten to know you, we'd like to learn more about your families. In your participant booklets on page 7 we'd like you to draw a picture of your family. Don't worry if you don't think that you're not a good drawer, just do your picture the way you want to or you can do a collage instead. We have some magazines, pictures and glue and scissors. We'll give you about 20 minutes to do this and then we'll introduce our families to the rest of the group.*

Allow participants around 20 minutes to draw or collage their family picture. Walk around and answer any questions, encourage participants. After everyone has finished, ask participants one by one to describe their picture and introduce their family to the rest of the group. You may like one of the facilitators to go first if no one wants to volunteer to go first.

*Thank you all for telling us about yourselves and your families today. Getting to know about each other's families is a great way to begin to understand each other. Next we are going to explore our ideas of who we are and who our siblings are.*

#### **4. Who Are We? (30 mins)**

Prepare two large sheets of paper with a question on each: one with "Who are we?" and the other with "Who are our siblings?" Break participants up into two groups. Present each group with one of the sheets. Tell them that their task is to write or draw an answer to the question as a team and after 10 mins that they will swap sheets with the other group. Have one facilitator guide each group with the task and then ensure the sheets are swapped after 10 minutes. Utilise the finished product to commence a brief discussion about what the next five formal group sessions will be addressing.

*You all did a GREAT job of expressing who you all are and who your siblings are on the posters. Teenagers who have a brother or sister with special needs often wonder about who they are and what it means to have a brother or sister with an intellectual disability. This session is about helping you to understand more about yourselves, your siblings and what it means to have a brother or sister with a disability. Next week we are going to look at what it means and what it's like for our siblings to have an intellectual disability and what your own strengths are as well as your sibling's.*

*We are going to meet back here at the same time next week. You can take your booklets home if you wish, however remember to bring them back! You may like to show your booklet to your mum/dad and talk about the group today or bring them in here to have a quick look at the posters that you made. We hope you have a lovely week and we look forward to seeing you next week.*

**Week 2:**

***Exploring Differences  
and Understanding  
Disabilities***

## Week 2: Exploring Differences and Understanding Disabilities

### **Outcomes:**

---

To explore the differences and similarities siblings have with their families and others

To build knowledge and understanding about disabilities

To enhance knowledge about personal strengths and the strengths of their siblings with a disability

### **Agenda:**

---

Getting to Know You  
Exploring Similarities and Differences  
Learning about Disabilities  
Exploring Strengths

### **Materials Needed:**

---

Pens  
Textas  
Cards with instructions  
Posters of group rules and objectives

### **1. Getting to Know You... (10 mins)**

As siblings enter, have them complete the family picture from last week.

*Welcome back everyone. How's your week been?*

Pin up the poster's from last week including the rules and objectives so everyone can see them. Revisit the rules and objectives of the group established last week.

*Hopefully you had a chance to learn a bit about everyone. Today we are going to start off with a quick game called Truth or Lie where you have to think back to what you learnt about others last week. Then we are going to look at the differences and similarities between us, our siblings, and others and then share what we know about disabilities. Lastly we are going to look at our strengths and things we enjoy doing. Are there any questions before we get started?*

### **Truth or Lie Game** (Adapted from Summers, Bridge and Summers, 1991)

Have participants sitting around in a circle.

*The first thing we are going to do is play Truth or Lie. Some of you may have played this game before. What you have to do is to think up a truth or lie about yourselves and the rest of the group has to decide if it's a truth or lie.*

Give group members a couple of minutes to think of something then go around the group and after each member has said their "truth or lie" the rest of the group has to decide if it is a truth or a lie.

## **2. Exploring Differences and Similarities (10 mins)**

*We are now going to look at differences and similarities. If you turn to page 10 of your participant booklet you will find a page title "Differences and Similarities". It asks you to complete the worksheet by listing 5 similarities and differences between yourself and your sibling and then your sibling and others in the community. Take about 5 minutes to complete the worksheet and then we will discuss it.*

### **Differences and Similarities**

Participants complete the worksheet, which asks them to write down 5 things that make them different and similar to their sibling, and 5 things that make their sibling with a disability similar and different to others in the community.

*What are the things that people have come up with? Who would like to read theirs out?*

Start a small discussion (5 mins) on people's answers and how different and similar they are to others and how these differences make them unique.

*If I can get two people to stand up. Chose 2 people with the same eye colour. Ok we have \_\_\_\_\_(name) and \_\_\_\_\_(name). What makes them to similar? Do you think that because they have similar \_\_\_\_\_ (list similarities) this makes them the same?*

Start a small discuss on how just because two people may have the same disability does not mean they do not have differences.

*Many people believe that people with the same disability means that act and behave the same. For example, that all people with Down syndrome must be really friendly and cuddle others all the time. But just like you and me have differences, just because people have the same disability doesn't mean that they are the same.*

### **3. Learning About Disabilities (40 mins)**

*Living with your brother or sister with a disability may mean that you know lots about disabilities, but there may be things that you don't understand.*

#### **Educating Others**

*In the past week we have learnt a bit about each other and each other's family and now we would like to learn about what you know about your brother or sister's disability. We'll go around the circle and finish the sentence "My brother or sister has \_\_\_\_\_ and that means \_\_\_\_\_"*

Allow participants a few moments to gather their thoughts and ask participants to share a small part of their sibling's story with the larger group by completing the sentence and explaining what they know about their sibling's disability. Prompt where necessary and provide lots of encouragement. Emphasis that they are experts and can educate others.

#### **More About Disabilities**

*You all have different understandings about intellectual disabilities and the particular disability that your brother or sister has. Basically, having an intellectual disability means that it is harder for the person to understand things.*

Discuss intellectual disability and causes briefly and address any concerns or questions that siblings may have.

*On page 11 of your booklets you will see an information sheet, which briefly outlines what it means to have an intellectual disability, what the causes of intellectual disability are, brief descriptions of a number of different types and then a list of contacts for further information.*

A copy of this information sheet is located in Appendix 1 for your information.

Then list the following concerns/myths about disabilities on the whiteboard and discuss with participants.

When I have children will they have a disability?

Will my brother/sister get better?

Will my brother/sister be able to get married?

Does that mean that there is something wrong with me too?

#### **4. Exploring Strengths (30 mins)**

*Now we all know a bit more about disabilities. We can see that there are things we are really good at and some things we aren't so good at so there are things, which our brother or sisters are good at, and some things that they aren't so good at. We are now going to have a look at our strengths and our brother or sisters strengths. Turn to page 15 and 16 of your books and spend 10 minutes completing the 2 worksheets. You may like to write these strengths or draw them.*

##### **Exploring Strengths**

*What are some of your sibling's strengths?*

Chose volunteers who would like to share their answers.

*What are some of your strengths?*

Chose volunteers who would like to share their answers.

##### **Things I Can Do With My Sibling**

*Thank you all for sharing that with us. Now that we have looked at our strengths as well as our brother or sisters strengths, we are going to look at ways of enjoying ourselves with and without our brother/sister. There is a worksheet on page 17 of your books for you to write down things you can do with your sibling. Once you have done this we'd like you to choose a partner and discuss your answers with them.*

Participants complete worksheets in booklet. Then discuss with a partner. Ask participants to jot down good ideas that they have heard from others.

## **Things I Can Do Without My Sibling**

*Next we will look at things you do without your sibling. On page 18 there is an activity sheet to complete. Once again, when you have finished this sheet we'd like you to pair up with someone- but someone you haven't been with before to discuss your answers.*

Participants complete worksheets in booklet. Then discuss with their new partner. Once again remind participants to write down good ideas that they have heard from others in their booklets.

*The reason we wanted you to look at things you can do with your sibling and things that you can do without them is, that you may often feel frustrated when you try to do something with you sibling that they are not so good at. Some of you may then try to help your sibling by for example, teaching them how to play the game or do whatever it is you are wanting to do with them. This is a good strategy. It's also good to think about things they can do well, their strengths, and play games or do activities where these strengths can be used. This can often make the activity more enjoyable for your sibling and make them feel good about themselves and can also make you feel good about it.*

*It's also important to look at things that you are really good at and how you can enjoy yourself without your sibling. It can be exhausting dealing with your brother or sister sometimes. If this is happening let you mum or dad know that you need some time-out. Arrange to do some of the things that you enjoy doing by yourself or others.*

*Thank you once again for sharing in the group. We hope you are enjoying attending the sessions and we will be talking about many more different things in the next few weeks.*

*If you have any questions about the groups or would like to talk about something in particular please let one of us know and we will try and include it. We hope you have a good week and look forward to seeing you next week!*

**Week 3:**

***Exploring and  
Communicating  
Feelings***

## Week 3: Exploring and Communicating Feelings

### **Outcomes:**

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To enhance awareness of feelings regarding having a brother or sister with a disability

To enhance family communication regarding challenging situations

To identify access when support is needed

### **Agenda:**

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Exploring feelings

Social Supports

Communicating Feelings

### **Materials Needed:**

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Pens

Highlighters

Jellybabies

Posters of group rules and objectives

Pin up the posters from last week including the rules and objectives so everyone can see them. Revisit the rules and objectives of the group established last week.

*Welcome back again. We hope you have enjoyed the last 2 weeks. Over the last 2 sessions we have gotten to know you a bit better and learnt a bit about your families. We have also learnt a bit more about disabilities, our strengths and the strengths of our siblings. What we are going to do today is to look at what it's like to be a sibling of a child with a disability.*

## **1. Exploring Feelings (45 mins)**

*Some of you are older siblings and others are younger than your brother or sister with a disability, some of you may be having a hard time and some of you may be having no troubles at all and that's OK. We are going to do some activities now exploring your feelings about what it's like for you. It's important to remember that we all have different feelings and experiences and some of you will feel the same as others in the group at times, but you also may feel quite different. That's OK- feelings are not "good" or "bad" they just are. So it's really important to remember our group rule of no put-downs in today's session.*

*Often siblings don't express the more negative feelings, especially at home for fear of worrying their parents even more, getting into trouble, or even feeling guilty about feeling that way. It is important that we express all of our feelings in a way that helps us cope and get on with our lives. We'll talk more about how you may do that later on.*

**Jellybaby Activity** (Adapted from Gilham, Jaycox, Reivich, Seligman, & Silver 1994)

Have two bowls of jellybabies ready with 3 colours in each bowl. Make one bowl represent "positive feelings" and the other represent negative feelings". For example Yellow Jellybaby = Happy; Orange Jellybaby = Surprised; Pink = Proud; Green jellybaby = Jealous; Red Jellybaby = Angry; Purple = Sad. The colours will differ depending what brand of jellybabies you buy.

*Next we have an activity, which we call the Jellybaby activity. We have 2 bowls of jellybabies and we are going to come around and ask you to chose one from each bowl.*

Walk around and let each participant chose one jellybaby from each bowl. Write on the whiteboard what each colour represents.

*Look at the colour of the jellybabies you have chosen. You will notice each jellybaby represents a feeling. We want you to look at the colour jellybabies you have and think about a time when you had that feeling. For example, I have a yellow jellybaby, which equals happy. A time I felt happy was the other day when I finished work an hour early and got to go to the beach. Who else has a yellow jellybaby?*

Ask those with the same colour to tell everyone about a time when they had that feeling. Then repeat the process with the other positive feelings one at a time and then repeat with the negative feelings. It's important to start off with the positive feelings and then explore the negative feelings. So repeat the process with the negative feelings next. It is also important that the facilitators participate in this group activity and participants are allowed to

pass if they don't want to share or if they can't think of something straight away as you can always go back to them later. Participants don't have to relate their feeling to an experience with their sibling just yet, however many will naturally do this. Protective interrupting may be needed if siblings start to disclose sensitive issues. How does everyone feel now?

### **Patchwork of Feelings**

*Thank you for sharing and we hope that you enjoyed the jellybabies. As you can see we all have positive and negative feelings in all kinds of situations. Having a brother or sister with an intellectual disability can lead to situations where we have both positive and negative feelings, so what we are going to do now is look at the feelings we can have.*

*If you turn to page 21 of your booklet, there is an activity called the Patchwork of Feelings. Listed here are many different feelings that siblings have told us in the past about what it is like to have a brother or sister with special needs. We'd like you to highlight the feelings on this sheet, which are relevant for you in the past week. Once you have done that we'd like you to partner up with someone else and discuss some of the situations where you had these feelings.*

Pass out highlighters. Participants spend 5-10 mins highlighting the feelings relevant on page 20 of their participant booklet and then discussing these with a partner. These can then be discussed in the larger group, emphasising how similarities and differences between participants and emphasising that all feelings are OK- it's how you manage the more difficult feelings that is important.

*So as you can see we all experience both positive and negative feelings and that's OK. It's what we do about the more challenging feelings that is important.*

## **2. Social Supports (30 mins)**

*Another thing that can often help us, which we talked a bit about in week 3, is talking to other people about what is worrying us or making us feel bad. One way of expressing these feelings is by communicating them with others. It's often easier to express the more positive feelings, however much harder to express the negative feelings to other people sometimes. This is because we are often worried about what other people will say, if we are going to hurt them by telling them how we feel or we may be worried we'll get into trouble if we tell someone. Sometimes it is difficult to talk to others such as our mum/dads as they are really busy and sometimes we don't want to bother others with our problems.*

*The people in our lives form what we call a support network and can be another way of helping us cope with difficult situations. A network is the people in our lives that share both the good and bad times. People in our network can help us in 5 different ways:*

- *By giving us good information*
- *In a practical way such as helping us with difficult homework*
- *Providing friendship*
- *Helping us with our emotions by accepting and listening to us- Both the good and the not so good feelings we have talked about; and*
- *Protecting us in stressful situations*

### **Hands of Support**

*We are now going to look at who is in our network and how close each person is to us. Turn to page 22 of your book and you will see an activity called Hands of Support. To complete this activity you need to firstly write your name in the first person, then in the next person, write the people who you are closest to, the third person is for people who are the next closest to you and so on until the outer circle where you write the names of those that you are the least close to. Go ahead and complete your hands of support now.*

Once participants have completed these, ask them to consider the types of support each of these people provide them with and how they have helped them in the past. Then discuss the different ways we behave towards each of these people. For example, those we are very close with we may hug, whereas we do not touch people we are not close to.

### **Other Supports**

Next list the types of people have in their network. Brainstorm other supports- ask participants to consider supports they haven't listed in their booklets. For example if group members haven't thought about teachers, classmates, close friends, sport coaches, family friends, neighbours, school counsellor, minister/pastor from church, doctor, psychologist.

Check that each participant has a few people in their network who do not live with them, such as uncles/aunts, family friends, neighbours, teachers.

*It is really important to have a few people outside of the home who can provide us with support if there is something difficult happening at home that we can't talk to our parents about. If you haven't been able to think of any or use any of the suggestions we have come up with there are always outside supports for teenagers such as those listed in your booklets on page 23 such as the KIDSHHELPLINE. There are also many websites set up for*

*siblings. Some of them have sibling discussion groups where you can talk to other siblings from all over the world. They are all safe networks and all emails are monitored before being sent to the network. The Sibling Project based in Adelaide has lots of information for siblings and a discussion group for younger and older siblings on their website at:*

*[www.wch.sa.gov.au/sibling](http://www.wch.sa.gov.au/sibling). The Sibling Support Project based in Seattle, Washington, also has a website specifically for siblings of children with special needs. There is an internet discussion group for younger brothers and sisters (Sibkids) and older brothers and sisters (SibNet). You can register to the discussion group or find out more information about these at: [www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport).*

### **3. Communicating Feelings (30 mins)**

*One way of expressing these feelings is by communicating them with others. It's usually pretty easy to express the more positive feelings, however much harder to express the negative feelings sometimes. Think back to the Patchwork of Feelings exercise we did earlier. How easy was it communicating the feelings to your partner?*

Elicit a few answers from participants.

*How easy is it for us to communicate with our parents, friends, teachers etc.?*

Elicit a few answers from participants.

*We often have difficulty expressing the more negative feelings we have as we are worried about what other people will say, if we are going to hurt them by telling them how we feel, that we may get into trouble or even feel guilty about feeling that way. However, it's really important that we are able to express these feelings to them so that they can help us if we need it and to avoid the feelings building up inside.*

*What can we do to make it easier to talk to parents about any difficulties we might be experiencing?*

Discuss strategies to overcome any barriers in talking about our feelings/problems with others.

*Thank you for sharing. Well it's almost time to go- how does everyone feel about the activities we did today? If anyone would like to talk to \_\_\_\_\_ or myself, please feel free to now or contact us during the week. We hope you have a great week and look forward to seeing you again next week!*

**Week 4:**

***Coping Skills 1***

## Week 4: Coping Skills 1

### **Outcomes:**

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To know and demonstrate problem-solving skills when facing challenging situations where participants may have some control over the outcome

### **Agenda:**

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The Problem-Solving Steps  
Problem-Solving in Practice

### **Materials Needed:**

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Blank cards  
Copies of role-play scenarios (Appendix 2)  
Posters of group rules and objectives

Pin up the poster's from last week including the rules and objectives so everyone can see them. Revisit the rules and objectives of the group established last week.

*Last week we talked about feelings, both positive and negative. Today we are going to talk about problems and how we can solve them. Having a brother or sister with special needs has many highs and lows, and sometimes a little help is needed when there is a problem. But it's often hard to work out what to do when we are faced with a really big challenge. So what we are going to talk about now is the steps to solving problems.*

# 1. The Problem-Solving Steps (50 mins)

## The Problem-Solving Steps

*There are 6 steps to solving problems:*

**STEP 1** Define the Problem: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**STEP 2** What do you want to happen? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**STEP 3** Who will be affected (eg. family, friends, teachers)? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**STEP 4** What options do I have and what are the pluses and minuses for myself and others?

| Options | SELF |   | OTHERS |   |
|---------|------|---|--------|---|
|         | +    | - | +      | - |
| _____   |      |   |        |   |
| _____   |      |   |        |   |
| _____   |      |   |        |   |
| _____   |      |   |        |   |

**STEP 5** What is the best option? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**STEP 6** What is my plan? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

***CHECK TO SEE IF THE PLAN HAS WORKED, IF NOT GO BACK TO STEP 4  
IF IT WORKED MAKE SURE YOU REWARD YOURSELF!***

Have 6 steps written on the whiteboard.

*The first step is working out what is the problem. You need to be specific here, for example, "My brother interrupts me when I am doing my homework" not, "My brother annoys me all the time". Next you have to decide what you want to happen. For example, your goal may be to "complete my homework in peace". Then work out who is involved, such as your brother/sister who is annoying you, your parents, your teacher etc. Then brainstorm as many options to solve this problem as possible. For example, "I could ignore him", "I could tell mum or dad", "I could lock my door" "I could do my homework after he goes to bed" or "I could put on his favourite video to keep him busy while I am doing my homework". Then you need to consider the pluses and minuses of each option for yourself and others. For example, "If I keep him busy he may stop annoying me, this is a plus for me; it may only work once or twice, this is a minus for me; a plus for him is that he gets to watch his favourite video; a minus for him is that "he may not be able to watch the whole movie and then may get upset". Do you understand how that works? The last steps are then to choose the best option and put a plan in action. For example, after going through all of the options I may decide that "keeping him busy with a video" may be the best option. I then have to put a plan into action, I could tell mum what I am going to do, I could get his favourite video ready and then put it on before I set up for my homework. After you have done this you need to check to see if the problem has gotten better, for example, have I been able to complete my homework in peace? If it has reward yourself! You deserve it! If the problem hasn't gotten better go back and chose another option and repeat the steps again.*

*Does that make sense to everyone? It may sound a bit hard to you now, but when we have a few goes at it you may find it gets easier. We also have put the steps in your book so that you can go back to them at any time to remind you what to do when you need to solve a problem. We are also going to have a practice with some really life problems that you have. We are going to hand out some blank cards and we want you to write down a problem that you need some help with. We don't want you to put you name on the card though, because we are going to shuffle them up and then go through each of them so we can have a practice of the problem-solving approach.*

Hand out blank cards to everyone and then collect them up ensuring confidentiality.

Go through the most commonly presented problem on the whiteboard (and others if time permits), asking group members to work out what the specific problem is, brainstorm ideas, evaluate the pluses and minuses and discuss a plan of action. If you go through each problem ask who if anyone else has had this problem before and what they tried (without identifying whose problem it is).

## **2. Problem-Solving in Practice (40 mins)**

*Solving problems can be hard at times. You now have had a little practice going through the 6 steps. What we are going to do now is break up into 4 groups and give you a problem situation. We'll ask you to go through the problem-solving steps with your group on page 26 of your booklets. Decide on the best option and we'd like you to role-play this situation and what you are going to do, to the rest of the group! We'll have about 20 minutes to work out your role-play and then we will ask you to do your role-play in front of the rest of the group. You can be as creative as you like!*

### **Role-Plays**

Break group members into 4 groups. Hand out one scenario (Appendix 2) per group. Check that all groups are on track and have an effective means of solving the problem.

**Note:** Slade (1988) suggests the process of using the situation presented by one or more participants and asking one group member to role-play a family member, such as the mother, with another group member or even the facilitator to role-play the child with a disability and another member to role-play the sibling, with a discussion about the role-play preceding it. Slade (1988) also suggests the possibility of swapping turns and asking others to take on the various roles and try to solve the problem in a different manner.

Allow 5 minutes for each group to present their situation and role-play. You may like to use "freeze-frames" whereby you stop the role-play at various times and ask group members to solve the problem from their or to comment on how the characters may be feeling. Hopefully all the role-plays were fun and participants are on a good note.

If aggression comes up, discuss the three different types of communication:

Passive

Aggressive

Assertive

Have the facilitators role-play each of these, looking at body language, speech, what is said and how the other person is responding. Emphasis the importance of respecting not only yourself and your family, but others through being assertive.

*Well we have covered a lot today. We hope you have been able to come up with some good strategies on how to deal with some of the challenging situations you face. We thank you all for supporting each other by suggesting ways of problem-solving some difficult situations of others. How is everyone feeling? As we have talked a lot about problems, you may feel*

*like you need to talk to someone after the session. We are happy for you to talk to one of us after the group or at another time. Otherwise you may want to talk to your mum or dad about the group, using the suggestions we went over last week. Next week we are going to go over ways of coping with situations we can't change. Don't forget to fill out the form on page 27 about what you learnt and enjoyed today. Thank you once again and we look forward to seeing you all again next week.*

**Week 5:**

***Coping Skills 2***

## Week 5: Coping Skills 2

### **Outcomes:**

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To identify and apply coping skills to deal with the more challenging times

### **Agenda:**

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Coping Skills  
Coping Skills in Practice

### **Materials Needed:**

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Relaxation scripts (Appendix 3)  
Posters on group rules and objectives

Put up posters of group rules and objectives.

*Welcome back! We are glad you could make it to week 5. Last week we talked about what it is like to have a brother or sister with special needs and how it is sometimes hard to tell others how we feel. We looked at ways of communicating these feelings to others in a helpful way. Did anyone have any thoughts about last week that they'd like to share now?*

Answer any questions or address any concerns.

*To start off today, lets look again at our group rules and what we all wanted to get out of them.*

Go through these both and discuss to the progress they have made so far. Point out the good things so far- sticking to the group rules etc.

*Today, we are going to talk about other ways of coping with the feelings we have about challenging situations. Sometimes, even after going through the problem solving steps we realise that we have no control over the challenging situation. In these cases we need ways of calming our own*

*feelings as well as actively solving problems or telling others our feelings. So today we are going to talk about ways of coping with these situations that we can't change.*

## **1. Coping Skills (60 mins)**

*By the word "coping" we mean what we do to make ourselves feel better. What are some situations where we may need to use coping skills?*

Listen and respond appropriately. You may need to add to these suggestions.

*We want you to turn to the first speech bubble on page 29 of your book and think of ways that you cope with difficult situations now. You can either write these or draw them.*

Give participants 5 minutes to list things that they do to cope now. Then elicit a discussion about this.

*What are some things that people do now when they are in a difficult situation and are feeling down?*

Elicit a discussion about coping strategies. Write responses on the whiteboard. For example, taking the dog for a walk, watching TV, listening to music, talking to someone about it, leaving the room, going to a friend's house, watching a funny movie.

*These are all good, however there are some other skills we can learn to use to cope with difficult situations. We can do what we call relaxation like deep breathing, what we call total muscle relaxation; visualisation or we can distract ourselves, have fun and laugh. Some of you have already mentioned distractions like watching TV, listening to music or taking the dog for a walk, or doing things that are fun such as watching a funny movie, but has anyone ever learnt any of the other relaxation skills like deep breathing or visualisation?*

List and respond appropriately. Then depending on whether or not they know or have learnt any of the skills chose at least 2 of the relaxation skills to teach the group using the scripts provided in the appendix 3 or your own technique.

- Deep Breathing
- Progressive Muscle Relaxation
- Guided Imagery

Ensure that all participants are comfortable, so this will mean moving chairs out of the way and generally re-arranging the room!

## **2. Coping Skills in Practice (40 mins)**

*Great, now we have learnt 2 (or 3) other ways of coping. We want you to learn these new ways of coping really well, so what we are going to do now is break up into pairs and practise using these skills on each other. We have about 10 minutes each to practise on of the activities, so chose one which you liked the best and decide who will go first. Then after 10 minutes we will ask you to swap with your partner, so if you were practising the activity, now you can be the one relaxing. The instructions we use for these relaxation exercises start on page 30.*

Refer participants to the scripts in their manuals. Explain procedures in more detail as required. Allow participants to move to a quiet spot. After 10 minutes remind participants to swap.

*Well done everyone. How did that feel?*

Allow for comments/questions.

*We hope you are feeling nice and relaxed after our exercises and be sure to practise them during the week. These exercises can be used a few times a week to help you cope better in general with challenging situations or you can use them at the time you are experiencing a stressful situation. It is often helpful to write down how you feel before and after using the exercise so you can see the benefits of using these skills.*

*Sometimes it can be tricky to use these coping skills at first but after lots of practise they are easy and can make you feel really good. So you may like to ask your mum/dad or someone else to do the relaxation exercise with you by reading the script, or you may like to memorise it so you can do it yourself. Another good way of using this is by tape-recording yourself reading the script. Otherwise you can buy relaxation tapes at different stores like the Dream factory in Subiaco or at the markets.*

*We also talked a bit about distraction before. We'd like to look a bit more at this. You can distract yourself by leaving the difficult situation by going for a walk etc., but sometimes we may be in a really difficult situation but we aren't able to leave. For example, your brother or sister may be "bugging" you at dinner. In this case you can distract yourself in your mind by say for example, by thinking about your favourite song, what you are going to do on your next holiday or a place you feel really safe.*

*Another way to feel good is using fun and laughter. Doing something that we find really fun, like what you wrote in your list in week 2, can often help us to feel better instantly. You have probably heard the saying that "laughter is the best medicine" and it can help us feel better in many situations by helping to release tension and can send endorphins around our bodies. Endorphins are hormones that make us feel good. Things that make us laugh are things like a funny movie, hearing or telling a funny joke; reading a joke book or comic or even dancing funny or singing or putting on a funny voice.*

### **What Else Can We Do?**

*Is there anything else that people do to make them feel better that we haven't talked about? Think back to what you wrote down in week 2 when we looked at enjoying ourselves without our sibling.*

Add any additional comments to the list on the whiteboard. Also discuss things like exercising/playing sport and spiritual means such as praying if no one has mentioned them.

*Now that we have talked about different ways of coping, we would like you to think about the best ways of coping for you and have heard today that you may like to do in the future that you don't already do. For example, you may have really liked our deep breathing exercise. Go back to page 29 of your book and fill out the bottom speech bubble by listing these things. Once again, you can either write or draw them.*

### **Leaving Activity**

*We have gone through lots of things today. To finish off we are going to play a quick game of Chinese Whispers.*

Start the Chinese Whispers game with a funny phrase using the names of participants in the group. Use the exercise to reinforce the message that fun and laughter can be a good way to get rid of stress and feel better.

*It's time to go now. We hope you are feeling nice and relaxed after our exercises and be sure to practise them during the week. These exercises can be used a few times a week to help you cope better in general with challenging situations or you can use them at the time you are experiencing a stressful situation. Be sure to write down how you feel before and after using the exercise.*

*There is a form on page 33 of your books to fill in for this week. In the meantime we hope you have a great week and we look forward to seeing you next week!*

**Week 6:**

***Finding Meaning***

## Week 6: Finding Meaning

### **Outcomes:**

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Review and reflect on past learning

Integrate past sessions to help participants find meaning in their situation

Evaluate group intervention

### **Agenda:**

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Integration of Information

Finding Meaning

Closure and Evaluation

### **Materials Needed:**

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Blank cards

2 large sheets of paper

Coloured textas

Ripped up paper/magazines

Glue

Posters for group rules and objectives

Pin up posters of group rules and objectives.

*Well we have reached our last group! We hope you have enjoyed yourselves, learnt lots of things and made some friendships so far. Today we are going to concentrate on you and your uniqueness and what you have learnt over the past 5 weeks. We know it's exciting that this is our last formal group, but it's important that we still stick to our rules of.....(go through rules) so we can achieve everything we need to.*

## **1. Integration of Information (35 mins)**

*We hope that you have learnt more about yourselves through this group and been able to better identify your strengths and resources.*

### **Our Uniqueness** (Adapted from McPhee & Westrup, n.d.)

*By now, we know quite a bit about each other, so we thought it would be fun to play a quick game. We are passing around some cards and textas and we would like you to write a description of yourself on your card in 10 words or less or draw something to represent yourself on it if you prefer. But don't put your name on your card and make sure no one peeks at it! When everyone has finished we are then going to shuffle them up and give them one out to everyone. The aim of the game is to guess as quickly as you can the identity of that unique person.*

Participants are given one card and texta and asked to write and/or draw descriptions of themselves on it. Remind participants that the descriptions must highlight their unique qualities, experiences and/or accomplishments. Cards are collected and shuffled and then randomly handed out. If one member receives their own card, ask them to close their eyes and switch cards. One by one ask the group members to read the card they have or show everyone its drawing and then the group tries to guess who the person is.

### **Picture of My Family**

*You may remember in the first group we asked you to draw a picture or do a collage of your family. We are going to ask you to this again to see if the way we view our family now is different from a few weeks ago.*

Allow participants 20 minutes to draw their family picture or do a collage. Walk around and answer any questions, encourage participants for their drawing, particularly if they don't enjoy or aren't skilled at drawing. After everyone has finished, ask participants to comment on how similar/different their drawing is from the one they did in the first week. Be specific and point out things if participants aren't able to, ask participants why those differences may be. If necessary put up this week's pictures against the other one's for comparison. Link changes to the range of activities and discussions the group has had throughout the last few weeks.

## **2. Finding Meaning (35 mins)**

### **Learning from Others**

*We hope you have learnt a lot over the last few weeks. We are going to spend a few minutes now thinking about this. We want you to think about what having a brother or a sister with a disability means to you. Remember in week one we did these posters (point to them) on who you are and who your siblings are? Now we'd like you to do something similar, getting into two groups, but this time we'd like you to consider what having a brother or sister with special needs means to you and what message you would like to give others who have just learned that they have a brother or sister with a disability to give them hope.*

Split the participants into 2 groups with one large sheet of paper each. Allow each group 10 minutes on their poster then swap with the other group. Facilitators assist each group with their creations! Invite participants to bring their parents in to look at the posters after the group session if they wish.

### **Finding meaning**

*Thank you everyone for doing these fantastic posters. We have accomplished a lot over the past 5 weeks and we'd like you to consider this now. On page 36 of your books you will find a sheet called Finding Meaning, which asks you to think about the groups. Please spend some time completing this now as well as the form for this week on page 37 and then we'll discuss it.*

Participants complete the individual activity integrating past activities. Questions include "What is the most important thing you have learnt?" "What was your favourite group and why?" "What was your least favourite group and why?" "What has changed since you have attended the groups?"

Once all participants have completed their sheet, elicit a large group discussion. Ask for volunteers to share with the rest of the group.

## **3. Closure (20 mins)**

### **Goodbye!!**

*It's come to the end of our last formal group now. However we are going to have our outing next week to celebrate all that we have achieved since we have known each other. We'll see you all then!!*

# **Appendix 1:**

## ***Information on Intellectual Disability***

## ***What is an Intellectual Disability?***

People with an intellectual disability have problems with their thinking, communicating with other people, learning and remembering things, making decisions and solving problems.

Some people have what we call a “mild intellectual disability” which means that they need help with only a few things in their everyday lives. Other people may have a “moderate disability” which means they need help with lots more things in their everyday lives and others with a “severe or profound intellectual disability” need help with almost every thing in their everyday lives.

Usually severe or profound intellectual disabilities are picked up in children at birth or at a very young age and they are recognised as having an intellectual disability, but sometimes milder intellectual disabilities may not be recognised in children until they start going to school. Some children that have an intellectual disability may also have what we call a “physical disability”.

## ***What Causes Intellectual Disability?***

There are many different reasons why people have an intellectual disability:

- “chromosomal and genetic reasons”
- infections that can cause intellectual disabilities
- metabolic disorders that can cause intellectual disabilities
- different toxics or poisons
- other things that can happen around the time of birth

But for over half of people who have an intellectual disability, we don't know why they have an intellectual disability.

## ***What Are Some of These Causes?***

### **Down syndrome**

Down syndrome is one of the most common causes of intellectual disabilities and one that you have probably heard of before. It can cause both intellectual and physical disabilities. Most people with Down syndrome, have good health, although they may be more likely than others to have problems with their sight or hearing, problems with their heart, and may go on to have leukaemia or thyroid problems.

### **Fragile X syndrome**

This is a syndrome that is inherited and many more boys than girls have this syndrome. People with this condition generally look just like everyone else however some may have features such as a long face, and ears, which stick out, a bit. People with this syndrome often have slower speech than others, may repeat things many times or stutter. They may show behaviours such as hand flapping, difficulty with eye contact and adapting to changes in their routines. People with Fragile x may also seem like they have lots more energy than others.

### **Prader-Willi syndrome**

This is a genetic disorder, which affects boys and girls equally. Young babies with this syndrome look a bit "floppy" and they usually are shorter than other children and have small hands and feet. They are often very hungry all the time and eat quite a bit. They can often be much larger than other children and get tired more easily than others. Children with Prader-Willi syndrome are generally happy people around others.

### **Angelman syndrome**

Just like people with Prader-Willi syndrome, Angelman syndrome is a genetic disorder. At birth they can often be floppy and have unusual jerky movements while they are young children. They generally have trouble communicating with others and can need help with things they need to do every day, like walking. Some children with Angelman syndrome also have Epilepsy. A lot of children with Angelman syndrome enjoy laughing a lot.

### **Williams syndrome**

Not many children have this syndrome, it is a very rare genetic disorder. Many people with Williams syndrome have a small upturned nose, wide mouth, full lips small chin and puffiness around their eyes. Many people with Williams syndrome also have heart problems. Children with Williams syndrome are known to have a unique way of expressing themselves and often enjoy the contact of adults rather than others their age.

### **Phenylketonuria (PKU)**

This is a very rare disease where the baby looks like other babies but end up with high levels of blood phenylalanine which leads to an intellectual disability because they can not metabolise the proteins in their food to absorb the goodness of the food they take in. All babies are screened for this problem just after birth and are placed on a strict diet, which can prevent disability.

### **Tuberous sclerosis**

Tuberous sclerosis affects people in different ways. While some people may be unaware they even have the condition, others may have a range of symptoms. About 1 in 2 people with Tuberous sclerosis have a learning disability and some have challenging behaviours. People with Tuberous sclerosis can have white patches on their skin, a rash on their face, epilepsy and tumours.

### **Rett syndrome**

This syndrome is one that only occurs in girls. They usually develop as other kids do until they are about 6-18 months old and then they can be slower to stand, crawl and walk than other children. They usually need to be cared for by others all the time.

### **Autism**

Some children with autism have an intellectual disability. There are four times as many boys than girls who have autism. The disorder affects part of the person's brain which makes it more difficult for them to communicate and understand people around them. Many children with Autism like to do the same things over and over again, usually in the same order. One of the greatest strengths of people with Autism is that they are visual learners so people with Autism can pick up many new skills when they are taught visually. Other strengths people with Autism may exhibit include, attention to detail and memory skills.

### **Cri Du Chat**

This is a very rare condition with almost all people with this condition having an intellectual disability. This condition is named Cri Du Chat or "cat's cry" because many children with this condition have a high-pitched cat-like cry. People with Cri Du Chat tend to have a smaller head than others, a round face, small chin, widely spaced eyes, and folds over their upper eyelids. These facial features typically change as children become teenagers. They are usually bright, loving and social children.

### ***Where Can I Go For More Information?***

Activ foundation has a great website with links to information about all disabilities. Their library website is: [www.activ.org.au/library.cfm](http://www.activ.org.au/library.cfm)

The Family Village has a website with information for people with special needs as well as for their families.

[www.familyvillage.wisc.edu/general/frc\\_sibl.htm](http://www.familyvillage.wisc.edu/general/frc_sibl.htm)

Carenet, a Melbourne based service for families with chronically ill children has a website with information for families at: [www.carenet.org.au](http://www.carenet.org.au)

*Information on the specific syndromes can be found from the following associations:*

#### Angelman Syndrome Association of WA

Liz Stanley (parent member)

Phone: (08) 9447 8606; Fax: (08) 9343 4431

E-mail: [cemec@bigpond.com](mailto:cemec@bigpond.com) ; Website: <http://www.angelmansyndrome.org>

Autism Association of Western Australia

37 Hay St Subiaco WA 6008; Locked Bag 9, Post Office West Perth 6872  
Phone: (08) 9489 8900 ; Fax: (08) 9489 8999  
Email: [autismwa@autism.org.au](mailto:autismwa@autism.org.au); Website: <http://www.autism.org.au>

Down Syndrome Association of Western Australia Inc.

4/1136 Albany Highway BENTLEY WA 6102, PO Box 338, Bentley WA 6982  
ph: (08) 9358 3544 free ph: 1800 623544 fax: 9358 3533  
Email: [dsawa@upnaway.com](mailto:dsawa@upnaway.com); Web Page <http://www.dsawa.asn.au>

Cri Du Chat Support Group of Australia Inc.

104 Yarralumla Dve, Langwarrin, VICTORIA. 3910  
Phone: (03) 9561 8134 or (03) 9775 9962; Fax: (03) 9791 8577 or (03) 9775 9962  
Email: [info@criduchat.asn.au](mailto:info@criduchat.asn.au); Website: <http://www.criduchat.asn.au>

Fragile X Support Group of WA

Leanne Pintaudi; 6 Burgandy Ct Thornlie 6108  
Phone: (08) 9493 4232; EMAIL: [leapin@hotmail.com](mailto:leapin@hotmail.com)

Prader Willi Syndrome Association of WA

Miss Kaye King (Co-ordinator)  
Phone: (08) 9375 8104; Email: [pwsa@kaysweb.com](mailto:pwsa@kaysweb.com)

PKU Association of NSW Inc.

Stephanie McConnell (Public Officer)  
Phone: (02) 9874 1536; EMAIL: [stephaniemcconnell@hotmail.com](mailto:stephaniemcconnell@hotmail.com)  
The Secretary, PKU Association of NSW, 28 Griffiths Street ERMINGTON NSW 2115  
Website: [www.pkunsw.org.au](http://www.pkunsw.org.au)

Australian Rett Syndrome Study

Telethon Institute for Child Health Research, PO Box 855 West Perth WA 6872  
Phone: (08) 9489 7790 EMAIL: [rett@ichr.uwa.edu.au](mailto:rett@ichr.uwa.edu.au)  
Website: [www.general.uwa.edu.au/u/hleonard/index.html](http://www.general.uwa.edu.au/u/hleonard/index.html)

Australasian Tuberous Sclerosis Society (ATSS) (WA Branch)

Judy Nicholls (President)  
5 Parer Ave CONDELL PARK NSW 2200; Phone: (02) 9707 2873  
EMAIL: [atss@netspace.com.au](mailto:atss@netspace.com.au); Website: <http://www.netspace.net.au/~atss/>

Williams Syndrome Family Support Group of WA Inc.

Rob Hendry (Secretary)  
6 Teak Way, MADDINGTON WA 6109  
Phone: (08) 9459 3716; Email: [wsfsgwa@tpgi.com.au](mailto:wsfsgwa@tpgi.com.au)

**Appendix 2:**  
***Scenarios for  
Role-Plays***

### **Scenario 1**

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You have made a new friend who suggests going to your house to watch a movie on the weekend. He/she doesn't know how your little brother/sister behaves when you have new people over. What do you do?

### **Scenario 2**

---

You decide to take your brother/sister into the city on the school holidays. While you are riding on the train, your brother/sister is really excited and starts getting loud. A few people look your way, however one person in particular keeps staring and won't keep their eyes off you. What do you do?

### **Scenario 3**

---

You are at school and it is lunchtime. The educational support class walks past where you are and your friends are sitting. One of your friends points at the educational support class and says "There are the *spastic kids*. Isn't your brother a *spastic*? That must mean you must be a *spastic*" The friend starts pulling faces and pretending to act like the kids in the educational support class. What do you do?

### **Scenario 4**

---

A friend is over at your house and you are both listening to your favourite music and gossiping about school. Suddenly, your brother/sister bursts into your room and starts dancing around and singing at the top of his/her lungs. Your friend looks at your brother or sister really weirdly and looks really uncomfortable. What do you do?

## **Appendix 3:**

# ***Scripts for Relaxation Exercises***



## **Deep Breathing**

*Ok now we are going to do some deep breathing exercises. First I want you to concentrate on your breathing. Are you breathing through your mouth or nose? Put your hand on your chest- is it beating fast or slow? Doing breathing exercises can help us slow down our breathing and focus our thoughts. It also brings oxygen to our brains helping us to think more clearly and have more energy. So this is a good exercise to do daily or when you are really worrying about something.*

*So here it goes. I want you to sit in a comfortable position with your hands placed just over your tummies. We put our hands over our tummies so that we can feel and see, if we have our eyes open, our deep breaths. I want your firstly to just take a normal breath in and out, in through your nose, out through your mouth. Look to see if your tummy is moving in and out, moving your hand with it. Feel your breath coming in like a wave, and going out like a crashing wave.*

Allow 1-2 mins for people to concentrate on their breathing.

*We are now going to do some deep breathing exercises. Most people only breath into their chest, but with deep breathing exercises we want to breath through your nose and pull your breaths right into your tummies for the count of four, then hold for four and breath out for four. You should be able to feel the breath coming into your tummy. Watch me.*

Demonstrate taking a deep breath.

*Sometimes it can be helpful to say something like "R-E-L-A-X" when you are breathing out or another word that makes you feel relaxed when you say it. OK, we'll now do the deep breathing exercise together as a group. Everyone ready? Hands on tummies and close your eyes just gently so nothing in the room can distract you. OK breath in pulling your breath all the way to your tummy, one, two, three, four, now hold, one, two, three, four, and out one, two, three, four.*

Repeat eight times. Then stop for 2 minutes and ask participants how they feel. Explain that it feels a bit strange at first because you are getting a lot more oxygen to your brain, but it gets easier and that feeling subsides after lots of practice. Repeat the above sequence one more time. Ask participants how they feel now- do they feel better than they did at the beginning? The middle? Congratulate them on a good job.



## Progressive Muscle Relaxation Script

*Gently and slowly close your eyes, now screw them up really tight, done that? now hold, a bit longer.....then relax them. Keep relaxing them..... Now scrunch them up again! And hold that,.....then let them go.....Feel how relaxed they are now.....Now we'll move on to your lips, press your lips together really tight, now hold that, then let them go.....Let them relax..... Do that one more time, press them together.....hold.....now let them relax. Now smile as widely as you can....., then hold,.....then relax. Feel your mouth and lips feeling relaxed.....now one more smile, nice and big.....hold.....and then relax. Relax your whole face..... Now on to your shoulders, pull them right up to your ears as if you are trying to touch them.....hold that.....keep holding.....a bit more.....now gently let them go. Now push them up again and hold.....hold.....now relax. Feel your shoulders getting heavy and relaxed.....Notice how different they feel from a few minutes ago. Now with your arms by your sides, scrunch your hands and fingers up into a fist. Hold them.....a bit longer,,now.....let them go. Let them relax..... Now scrunch them up again, like you are holding something that you don't want to let go....., hold.....then relax. Now let your arms, hands and fingers go all loose like they are really heavy.....let them just relax.....Now pull in your tummy....., hold it tight and take a big breath..... then relax and breath out.....Notice your tummy feeling nice and relaxed. OK one more time, pull in your tummy tight, breathing in..... hold.....now let it go.....,, breathing out, notice how different it feels now. On to your legs now. Tense them up really tight, keeping them as straight as you can, pull your feet back as far as they'll go, curl your toes up.....hold now.... then let them go.... Let them relax now..... Once again, straighten your legs so they're really tight, pull your feet back, curl your toes right under those feet and breathing in....hold.....then breath out and let them all go loose. Notice how heavy and relaxed they feel now.....Now the last thing to do is tense up your whole body, from your eyes where we started, over your lips and mouth, .....shoulders.....fists..... .stomach....legs, feet and toes so your whole body is now really stiff. Hold it..... Then let everything go loose and floppy. Feel your whole body relax. One more time.... tighten your whole body from your eyes to your toes.....hold..... hold a bit more..... Then relax.....let your whole body go loose. Notice how different it feels now....everything feeling heavy, loose, more relaxed. Enjoy this new relaxed feeling. Remembering to control your breaths in, holding them, then breathing out. Are there any spots that are still a bit sore? Or is your whole body relaxed? Keep on feeling your whole body relaxed for a few moments now.*

Wait 1-2 minutes.

*OK, now slowly stretch out your arms and legs, keeping your eyes still closed. Then roll on your side, making sure you don't roll on to anyone next to you. Now open your eyes on the count of 5. 1...2...3...4...5. Well done, when you are ready slowly get up.*



## Guided Imagery Script

*OK, now get into your most comfortable position, gently close your eyes and listen to what I am saying. We are going to spend a few minutes thinking about a nice special place for yourselves. Somewhere where you feel totally relaxed, happy and safe. I want you to think about that special place in your head .... It might be at the beach, in the forest, on an island, at the park, on a farm or even in the middle of a big field. I want you to concentrate now and picture your special place in your head.....(Pause about 10 seconds). Now that you have a picture in your mind, I want you to look around your special place, what are the colours you see? (Pause about 10 seconds) What smells are there in the air? (Pause about 5 seconds) Feel the air on your skin in this special place (Pause about 5 seconds) and the ground underneath you (Pause about 10 seconds). Are there any sounds in your special place? (Pause about 5 seconds)..... Listen to them.....Feel yourself in this special place. (Pause for about 10 seconds). Feel how relaxed, happy and safe you feel in this special place. Let yourself look around your special place a bit more. (Pause for about 20 seconds). Let yourself run, skip, dance, walk, swim or fly around in this place. (Pause for about 20 seconds). Let that feeling of happiness and calm from your special place fall over you like a wave. Let your whole body feel relaxed and peaceful in this special place for a few minutes. Allow a minute to lie in this spot.*

*Now it's almost time to leave your special place. In your mind, I want you to walk around the area of your special place and wave. Wave to everything in your special place. Wave to any trees, birds, rivers, oceans, clouds and skys. (Pause for about 5 seconds). You will return to this special place again soon. (Pause for about 5 seconds). Now it's time to leave.....I want you to notice the sounds coming back to you from the sibling group. Feel what you are laying on. (Pause for about 5 seconds). Feel the air on your skin (Pause for about 5 seconds). Here the noises from outside. (Pause for about 5 seconds). Gently wiggle your fingers and your toes. Stretch your body out. S-t-r-e-t-ch, and now relax. Roll onto your left side and stretch a bit more. Roll onto your right side and stretch. Now as I begin to count, slowly begin to open your eyes. ...1...2...3...4...5. When you are ready stand up and stretch, up and up. Touch the roof, touch the side walls, now the ground. It's good to stretch. Well done everyone. How did that feel?*

**Appendix 4:**

***Parent Information  
Sheets***



## **Parent Information Sheet**

### ***Week 1: Sharing My Story***

One of the longest lasting relationships in our lives is the one we have with our brothers or sisters. Our brothers and sisters keep us company, give us support and help us learn about other people.

As a teenager, life can be tough at times, and having a brother or sister with a disability in our lives can sometimes add more stress to their lives. These challenges can make teenagers stronger but sometimes they can be quite difficult. On the good side, brother and sisters with a disability can teach siblings to be more patient, tolerant of other people, and be more mature and responsible. They can also help siblings to be more appreciative of their own good health and intelligence and feel proud of their brother or sister with special needs.

However, sometimes siblings may feel their brother or sister with special needs receives more attention than them. Some siblings have also said that they are embarrassed by their behaviours or have difficulty explaining their brother or sister's disability to others. Siblings often have mixed feelings about having a brother or sister with special needs and this is OK. Every teenager who has a brother or sister with a disability has a unique experience so it can be helpful to talk to other siblings about what life is like for them.

The aim of these sibling groups is for teenage siblings to meet others in a similar situation to share their feelings and experiences. In coming groups we will help siblings to explore their strengths as well as the strengths of their siblings, look at the various feelings they have about being a sibling, look at problem-solving some of the more challenging situations they may face and explore various coping styles. Overall we hope to help siblings understand that they are very special and are valuable members of our community.

In this week's group siblings had the opportunity to start telling their story in a safe supportive environment and spent time introducing themselves and learning a bit about each other. They also started the process of developing their identities of themselves as siblings and understanding more about their brother or sister with a disability is.



## **Parent Information Sheet**

### ***Week 2: Exploring Differences and Understanding Disabilities***

Many siblings are curious about their brother or sister's disability and may ask you questions about it. Others may be too embarrassed or are unsure of how to ask. This week's group focused on getting rid of some of the common misconceptions about disabilities. The issue of "being different" was explored and each sibling shared their knowledge about their brother or sister's disability. "Intellectual disability" can often be a confusing term, so we undertook some activities exploring what it means, what the causes of intellectual disability are and how it might feel for those with an intellectual disability. Questions that we explored included:

When I have children will they have a disability?  
Will my brother/sister get better?  
Will my brother/sister be able to get married?  
Does that mean that there is something wrong with me too?

Next we looked at the strengths of siblings as well as the strengths of their brother or sister. We then used this information to brainstorm activities that siblings can enjoy with and without their sibling. The reason we look at both types of activities that siblings can do with and without their sibling is that sometimes siblings may feel frustrated when they try to do something with their sibling and it doesn't go to plan. There are many reasons for this, including the sibling not understanding the activity so it's often helpful for siblings to think the strengths of their brother or sister, and arrange games or activities where these strengths can be used. This can often make the activity more enjoyable for your child with special needs as well as their sibling. It's also important to look at things that siblings are really good at and how they can enjoy themselves without their brother or sister with special needs as it can be exhausting dealing with their brother or sister sometimes. When this occurs siblings need some time-out. Arrange for them to do some of the things that they enjoy doing by themselves or going for a visit to a friends or relatives house can be very helpful.



## Parent Information Sheet

### ***Week 3: Exploring and Communicating Feelings***

Siblings can experience many different feelings about having a brother or a sister with a disability- they can feel important, happy, content, proud, tolerant, appreciated, curious, responsible, confused, frustrated, angry, lonely, guilty, resentful, jealous, protective, worried.....

All of these feelings are normal. However often siblings don't express the more "negative" feelings, especially at home for fear of worrying their parents even more, getting into trouble, or feeling guilty about having those feelings. The message for this week was that it is OK for siblings to have positive and negative feelings and it's important that we express these feelings in a way that helps us cope and get on with our lives.

We focused on this message by allowing siblings to share their feelings, and also information and advice about how they deal with some of the more challenging experiences of being a sibling. As well as knowing it is OK to talk about both positive and more negative feelings, we explored the support networks that siblings have.

A support network is the people in our lives that we can share both the good and bad times with and can help us when we are in a difficult situation.

People in our network can help us in 5 different ways:

- *By giving us good information*
- *In a practical way such as helping us with difficult homework*
- *Providing friendship*
- *Helping us with our emotions by accepting and listening to us- Both the good and the not so good feelings we have talked about*
- *Protecting us in stressful situations*

Next we discussed difficulties we have sometimes communicating with people in our network and how to overcome this. This included ways siblings can talk to their parents about their feelings, for example, by talking to them when there are no other distractions, such as when their brother or sister has gone to bed, making a time once a week to talk about things that come up or writing a letter. You may want to brainstorm ways of helping your sibling communicate their feelings about the more difficult situations to you.



## Parent Information Sheet

### *Week 4: Coping Skills 1*

Last week's group concentrated on feelings, both positive and negative. Having a brother or sister with special needs has many highs and lows, and sometimes a little help is needed when there is a problem. But it's often hard to work out what to do. This week's group focused on problem solving. We looked at the 6 steps and the conducted role-plays looking at various scenarios teenage siblings typically face

The 6 steps to problem-solving that we discussed are listed below:

**STEP 1**      Define the Problem: \_\_\_\_\_

**STEP 2**      What do you want to happen? \_\_\_\_\_

**STEP 3**      Who will be affected (eg. family, friends, teachers)? \_\_\_\_\_  
\_\_\_\_\_

**STEP 4**      What options do I have and what are the pluses and minuses for myself and others?

|         | SELF |   | OTHERS |   |
|---------|------|---|--------|---|
| Options | +    | - | +      | - |
|         |      |   |        |   |
|         |      |   |        |   |
|         |      |   |        |   |

**STEP 5**      What is the best option? \_\_\_\_\_

**STEP 6**      What is my plan? \_\_\_\_\_

***THEN CHECK TO SEE IF THE PLAN HAS WORKED, IF NOT GO BACK TO  
STEP 4  
IF IT WORKED MAKE SURE YOUR REWARD YOURSELF!***



## **Parent Information Sheet**

### **Week 5: Coping Skills 2**

In the last couple of weeks we have talked about positive and negative feelings and challenging experiences. We have also talked about ways that we may be able to problem-solve the more difficult situations. However, sometimes we are not in control of the difficulties we face in life but we still have to cope with our feelings associated with the situation. Therefore, this week's session concentrated on learning ways of coping with situations that we can't change.

There are many different ways of coping, which we explored in this week's group. Firstly we introduced the use of relaxation skills like deep breathing, total muscle relaxation and visualisation. Total muscle relaxation involves systematically tensing and releasing each of the major muscles in our bodies, helping us to feel a total body relaxation. Visualisation involves closing your eyes and focusing on an imaginary scenario presented. Visualisation helps us to avoid distractions or worrying thoughts and takes us to a relaxing place in our minds. It is a helpful exercise to be used daily or whenever one is feeling stressed or worried. Siblings have copies of all the scripts used in the relaxation group, so that they can practice at home or teach someone else about relaxation.

Another type of coping, which we explored, is the use of distraction, physical exercise and fun and laughter. Distractions are things like watching TV, listening to music, taking the dog for a walk etc. Physical exercise can also help release tension within the body. Another way to feel good is using fun and laughter. Doing something that we find really fun, can often help us to feel better instantly. You have probably heard the saying that "laughter is the best medicine" and it can help us feel better in many situations by helping to release tension. Things that make us laugh are things like a funny movie, hearing or telling a funny joke; reading a joke book or comic; dancing or singing funny; or putting on a funny voice.



## **Parent Information Sheet**

### ***Week 6: Finding Meaning***

This week was the last formal session in our 6-week program. Therefore we focused on how each sibling is important and unique and did a fun activity to highlight each sibling's uniqueness. We also reviewed what we had done in previous groups and looked at what siblings felt they had gained in the groups. Questions addressed included:

"What is the most important thing you have learnt?"

"What has changed since you have attended the group?"

"What group did you enjoy the most and why?"

"What group did you enjoy the least and why?"

The focus here was on integrating the information and skills learnt to create a more positive meaning about being a sibling of a child with a disability. We explored what it means for siblings and what advice they would like to share with other siblings. We also looked at the friendships siblings had made and swapped contact details so those friendships could continue.

*Thank you for supporting your teenage child/children by helping them to attend this six-week group program. We hope siblings have gained a lot from the groups and that it has been a positive experience, which helps them to continue to grow and develop as unique and valued members of our community. Next week we will be celebrating all siblings have achieved with a group outing!*

Warm regards,

Monique

Monique Nesa  
Sibs and Us Project  
Curtin University of Technology  
(08) 9266 3446

**Appendix 5:**

***Participant Family  
Information Record***

Participant Name: \_\_\_\_\_ Participant Age: \_\_\_\_\_  
People living in home: \_\_\_\_\_  
Name of brother or sister/s with disability: \_\_\_\_\_  
Age of brother or sister/s with disability: \_\_\_\_\_  
Type of disability/s: \_\_\_\_\_

---

Participant Name: \_\_\_\_\_ Participant Age: \_\_\_\_\_  
People living in home: \_\_\_\_\_  
Name of brother or sister/s with disability: \_\_\_\_\_  
Age of brother or sister/s with disability: \_\_\_\_\_  
Type of disability/s: \_\_\_\_\_

---

Participant Name: \_\_\_\_\_ Participant Age: \_\_\_\_\_  
People living in home: \_\_\_\_\_  
Name of brother or sister/s with disability: \_\_\_\_\_  
Age of brother or sister/s with disability: \_\_\_\_\_  
Type of disability/s: \_\_\_\_\_

---

Participant Name: \_\_\_\_\_ Participant Age: \_\_\_\_\_  
People living in home: \_\_\_\_\_  
Name of brother or sister/s with disability: \_\_\_\_\_  
Age of brother or sister/s with disability: \_\_\_\_\_  
Type of disability/s: \_\_\_\_\_

---

Participant Name: \_\_\_\_\_ Participant Age: \_\_\_\_\_  
People living in home: \_\_\_\_\_  
Name of brother or sister/s with disability: \_\_\_\_\_  
Age of brother or sister/s with disability: \_\_\_\_\_  
Type of disability/s: \_\_\_\_\_

---

Participant Name: \_\_\_\_\_ Participant Age: \_\_\_\_\_  
People living in home: \_\_\_\_\_  
Name of brother or sister/s with disability: \_\_\_\_\_  
Age of brother or sister/s with disability: \_\_\_\_\_  
Type of disability/s: \_\_\_\_\_

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*Websites used for information on disabilities:*

[www.activ.org.au/library.cfm](http://www.activ.org.au/library.cfm)

[www.autismnsw.com.au/about%20autism/whatis.asp](http://www.autismnsw.com.au/about%20autism/whatis.asp)

[www.autism.org.au/faq.htm](http://www.autism.org.au/faq.htm)

[www.betterhealth.vic.gov.au/bhcarticles.nsf/pages/Rett\\_syndrome\\_affect...](http://www.betterhealth.vic.gov.au/bhcarticles.nsf/pages/Rett_syndrome_affect...)

[www.betterhealth.vic.gov.au/bhcarticles.nsf/pages/Phenylketonuria](http://www.betterhealth.vic.gov.au/bhcarticles.nsf/pages/Phenylketonuria)

[www.criduchat.asn.au/criduchat/what.htm](http://www.criduchat.asn.au/criduchat/what.htm)

[www.cyh.com/cyh/parenttopics/admin\\_srchl2.stm?topic\\_id=1565](http://www.cyh.com/cyh/parenttopics/admin_srchl2.stm?topic_id=1565)

[www.duit.uwa.edu.au/web/inclusion/disability/RettS.html](http://www.duit.uwa.edu.au/web/inclusion/disability/RettS.html)[www.ninds.nih.gov/health\\_and\\_medical/pubs/rett.htm](http://www.ninds.nih.gov/health_and_medical/pubs/rett.htm)

[http://hmb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/pub\\_intellect](http://hmb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/pub_intellect)

<http://home.vicnet.net.au/~wsfg/>

[www.rettsyndrome.net/](http://www.rettsyndrome.net/)

[www.netspace.net.au/~atss/tsc.htm](http://www.netspace.net.au/~atss/tsc.htm)

[www.pws.org.au/general.html](http://www.pws.org.au/general.html)

[www.williamsyndrome.org/forparents/whatiswilliams.html](http://www.williamsyndrome.org/forparents/whatiswilliams.html)

[www.1uphealth.com/health/phenylketonuria\\_info.html](http://www.1uphealth.com/health/phenylketonuria_info.html)

# The Sibs and Us Project



## Participant Booklet

Written by Monique Nesa

## Forward

---

One of the longest lasting relationships in our lives is the one we have with our brothers or sisters. Our brothers and sisters keep us company, give us support and help us learn about other people.

As a teenager, life can be tough at times, and having a brother or sister with a disability in our lives can sometimes be an extra challenge. The challenges can be good and sometimes they can be quite difficult. On the good side, brother and sisters with a disability can teach you to be more patient, tolerant of other people, and be more mature and responsible. They can also make us feel really proud of them.

However, sometimes brothers or sisters with a disability can get more attention. This is often because they may need more help with things in their everyday lives than you do. Some siblings have also said that they are embarrassed by their behaviours sometimes. Every teenager who has a brother or sister with a disability has a unique experience so it can be helpful to talk to other siblings about what life is like for them.

That is why we have set up the group you are attending. You will be able to share your stories; you may be able to help other siblings who are finding their situation particularly challenging or you can pick up some strategies on how to cope with the more difficult times yourself. Also, we hope that you have lots of fun!

## Acknowledgements

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### Funding:

Disability Services Commission, Metropolitan and Country Services Directorates

### Contributors:

Associate Professor Clare Roberts  
Professor David Hay  
Mairead McCoy  
John Dockerill  
Kate Ollier  
Melinda Andrews

### Artwork:

Stuart Clipston

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**Week 1:**

***Sharing My Story***

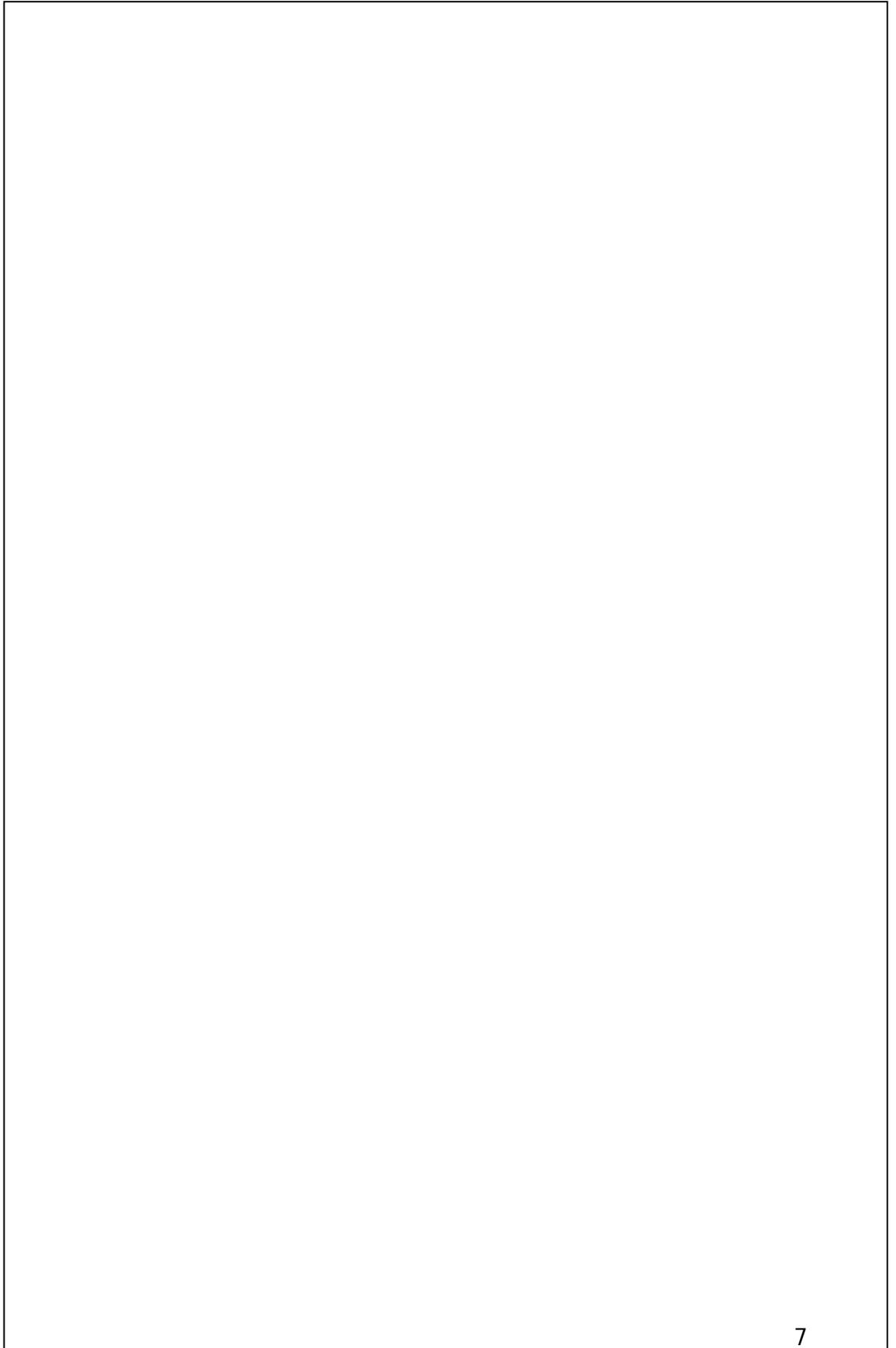


Find Someone Who.....

- Has seen Lord of the Rings \_\_\_\_\_
- Loves chocolate \_\_\_\_\_
- Has been to Sydney \_\_\_\_\_
- Watches Big Brother \_\_\_\_\_
- Has been to a concert \_\_\_\_\_
- Has 2 brothers \_\_\_\_\_
- Prefers reading to watching TV \_\_\_\_\_
- Plays video games \_\_\_\_\_
- Can wolf whistle \_\_\_\_\_
- Likes football \_\_\_\_\_
- Can draw well \_\_\_\_\_
- Likes going to the beach \_\_\_\_\_
- Is wearing red \_\_\_\_\_
- Has blue eyes \_\_\_\_\_
- Likes Eminem \_\_\_\_\_
- Plays more than one sport \_\_\_\_\_
- Shares a room \_\_\_\_\_
- Hates broccoli \_\_\_\_\_
- Can roll their tongue \_\_\_\_\_
- Has curly hair \_\_\_\_\_
- Speaks another language \_\_\_\_\_
- Has a part-time job \_\_\_\_\_
- Can pat their head and rub their  
stomach at the same time \_\_\_\_\_

## Picture of My Family

Draw picture of your family in the box below. Be as creative as you like!





## Week 1

What did you learn in Week 1? \_\_\_\_\_

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How will this help you and/or your sibling? \_\_\_\_\_

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What activity/discussion did you enjoy the most and why? \_\_\_\_\_

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---

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What activity/discussion did you enjoy the least and why? \_\_\_\_\_

---

---

---

What would you change about Week 1? \_\_\_\_\_

---

---

---

**Week 2:**

***Exploring Differences  
and Understanding  
Disabilities***

## Exploring Differences and Similarities

Write down 5 things that you have in common with your sibling with special needs and 5 things that are different; then write down 5 things that make your sibling with special needs different from other kids and 5 things that they have in common with others kids.

### My Sibling and I

#### **Things in common different**

1.

2.

3.

4.

5.

#### **Things that are**

1.

2.

3.

4.

5.

### My Sibling and Others

#### **Things that are different**

1.

2.

3.

4.

5.

#### **Things in common**

1.

2.

3.

4.

5.

## ***What is an Intellectual Disability?***

People with an intellectual disability have problems with their thinking, communicating with other people, learning and remembering things, making decisions and solving problems.

Some people have what we call a “mild intellectual disability” which means that they need help with only a few things in their everyday lives. Other people may have a “moderate disability” which means they need help with lots more things in their everyday lives and others with a “severe or profound intellectual disability” need help with almost every thing in their everyday lives.

Usually severe or profound intellectual disabilities are picked up in children at birth or at a very young age and they are recognised as having an intellectual disability, but sometimes milder intellectual disabilities may not be recognised in children until they start going to school. Some children that have an intellectual disability may also have what we call a “physical disability”.

## ***What Causes Intellectual Disability?***

There are many different reasons why people have an intellectual disability:

- “chromosomal and genetic reasons”
- infections that can cause intellectual disabilities
- metabolic disorders that can cause intellectual disabilities
- different toxics or poisons
- other things that can happen around the time of birth

But for over half of people who have an intellectual disability, we don't know why they have an intellectual disability.

## ***What Are Some of These Causes?***

### **Down syndrome**

Down syndrome is one of the most common causes of intellectual disabilities and one that you have probably heard of before. It can cause both intellectual and physical disabilities. Most people with Down syndrome have good health; although they may be more likely than others to have problems with their sight or hearing, problems with their heart, and in some instances go on to have leukaemia or thyroid problems.

### **Fragile X syndrome**

This is a syndrome that is inherited and many more boys than girls have this syndrome. People with this condition generally look just like everyone else however some may have features such as a long face, and ears that stick out a bit. People with this syndrome often have slower speech than others, may repeat things many times or stutter. They may show behaviours such as hand flapping, difficulty with eye contact and adapting to changes in their routines. People with Fragile X may also seem like they have lots more energy than others.

### **Prader-Willi syndrome**

This is a genetic disorder, which affects boys and girls equally. Young babies with this syndrome look a bit “floppy” and they usually are shorter than other children and have small hands and feet. They are often very hungry all the time and eat quite a bit. They can often be much larger than other children and get tired more easily than others. Children with Prader-Willi syndrome are generally happy people around others.

### **Angelman syndrome**

Just like people with Prader-Willi syndrome, Angelman syndrome is a genetic disorder. At birth they can often be floppy and have unusual jerky movements while they are young children. They generally have trouble communicating with others and can need help with things they need to do every day, like walking. Some children with Angelman syndrome also have Epilepsy. A lot of children with Angelman syndrome enjoy laughing a lot.

### **Williams syndrome**

Not many children have this syndrome, it is a very rare genetic disorder. Many people with Williams syndrome have a small upturned nose, wide mouth, full lips small chin and puffiness around their eyes. Many people with Williams syndrome also have heart problems. Children with Williams syndrome are known to have a unique way of expressing themselves and often enjoy the contact of adults rather than others their age.

### **Phenylketonuria (PKU)**

This is a very rare disease where the baby looks like other babies but end up with high levels of blood phenylalanine which leads to an intellectual disability because they can not metabolise the proteins in their food to absorb the goodness of the food they take in. All babies are screened for this problem just after birth and are placed on a strict diet, which can prevent disability.

### **Tuberous sclerosis**

Tuberous sclerosis affects people in different ways. While some people may be unaware they even have the condition, others may have a range of symptoms. About 1 in 2 people with Tuberous sclerosis have a learning disability and some have challenging behaviours. People with Tuberous

sclerosis can have white patches on their skin, a rash on their face, epilepsy and tumours.

### **Rett syndrome**

This syndrome is one that only occurs in girls. They usually develop as other kids do until they are about 6-18 months old and then they can be slower to stand, crawl and walk than other children. They usually need to be cared for by others all the time.

### **Autism**

Some children with autism have an intellectual disability. There are four times as many boys than girls who have autism. The disorder affects part of the person's brain which makes it more difficult for them to communicate and understand people around them. Many children with Autism like to do the same things over and over again, usually in the same order. One of the greatest strengths of people with Autism is that they are visual learners so people with Autism can pick up many new skills when they are taught visually. Other strengths people with Autism may exhibit include, include attention to detail and memory skills.

### **Cri Du Chat**

This is a very rare condition with almost all people with this condition having an intellectual disability. This condition is named Cri Du Chat or "cat's cry" because many children with this condition have a high-pitched cat-like cry. People with Cri Du Chat tend to have a smaller head than others, a round face, small chin, widely spaced eyes, and folds over their upper eyelids. These facial features typically change, as children become teenagers. They are usually bright, loving and social children.

### ***Where Can I Go For More Information?***

Activ foundation has a great website with links to information about all disabilities. Their library website is: [www.activ.org.au/library.cfm](http://www.activ.org.au/library.cfm)

The Family Village has a website with information for people with special needs as well as for their families.

[www.familyvillage.wisc.edu/general/frc\\_sibl.htm](http://www.familyvillage.wisc.edu/general/frc_sibl.htm)

Carenet, a Melbourne based service for families with chronically ill children has a website with information for families at: [www.carenet.org.au](http://www.carenet.org.au)

*Information on the specific syndromes can be found from the following associations:*

#### Angelman Syndrome Association of WA

Liz Stanley (parent member)

Phone: (08) 9447 8606; Fax: (08) 9343 4431

E-mail: [cemec@bigpond.com](mailto:cemec@bigpond.com) ; Website: <http://www.angelmansyndrome.org>

Autism Association of Western Australia

37 Hay St SUBIACO WA 6008; Locked Bag 9, Post Office WEST PERTH WA 6872

Phone: (08) 9489 8900 ; Fax: (08) 9489 8999

Email: [autismwa@autism.org.au](mailto:autismwa@autism.org.au); Website: <http://www.autism.org.au>

Cri Du Chat Support Group of Australia Inc.

104 Yarralumla Dve, Langwarrin, VICTORIA. 3910

Phone: (03) 9561 8134 or (03) 9775 9962; Fax: (03) 9791 8577 or (03) 9775 9962

Email: [info@criduchat.asn.au](mailto:info@criduchat.asn.au); Website: <http://www.criduchat.asn.au>

Fragile X Support Group of WA

Leanne Pintaudi; 6 Burgandy Ct Thornlie 6108

Phone: (08) 9493 4232; EMAIL: [leapin@hotmail.com](mailto:leapin@hotmail.com)

Prader Willi Syndrome Association of WA

Miss Kaye King (Co-ordinator)

Phone: (08) 9375 8104; Email: [pwswa@kaysweb.com](mailto:pwswa@kaysweb.com)

PKU Association of NSW Inc.

Stephanie McConnell (Public Officer)

Phone: (02) 9874 1536; EMAIL: [stephaniemccconnell@hotmail.com](mailto:stephaniemccconnell@hotmail.com)

The Secretary, PKU Association of NSW, 28 Griffiths Street ERMINGTON NSW 2115

Website: [www.pkunsw.org.au](http://www.pkunsw.org.au)

Australian Rett Syndrome Study

Telethon Institute for Child Health Research, PO Box 855 West Perth WA 6872

Phone: (08) 9489 7790 EMAIL: [rett@ichr.uwa.edu.au](mailto:rett@ichr.uwa.edu.au)

Website: [www.general.uwa.edu.au/u/hleonard/index.html](http://www.general.uwa.edu.au/u/hleonard/index.html)

Australasian Tuberous Sclerosis Society (ATSS) (WA Branch)

Judy Nicholls (President)

5 Parer Ave CONDELL PARK NSW 2200; Phone: (02) 9707 2873

EMAIL: [atss@netspace.com.au](mailto:atss@netspace.com.au); Website: <http://www.netspace.net.au/~atss/>

Williams Syndrome Family Support Group of WA Inc.

Rob Hendry (Secretary)

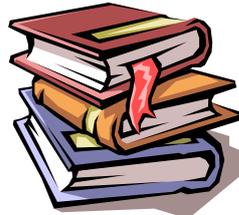
6 Teak Way, MADDINGTON WA 6109

Phone: (08) 9459 3716; Email: [wsfsgwa@tpgi.com.au](mailto:wsfsgwa@tpgi.com.au)

## My Strengths

Think about what your strengths are in the areas listed below. They may be strengths of character, for example patience, or they may be skills you have, for example, a good swimmer. Write or draw these strengths in the boxes below.

In my family



At school

Physical  
Appearance



With

others



At Sports

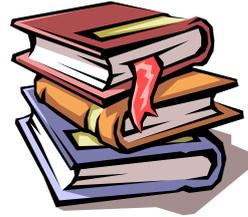


My Behaviour

## My Sibling's Strengths

Now that you have explored your strengths, think about what your sibling's strengths are. Once again, they may be strengths of character or they may be skills they have. Write or draw these strengths in the boxes below.

In my family



At school

Physical  
Appearance



With

others



At Sports

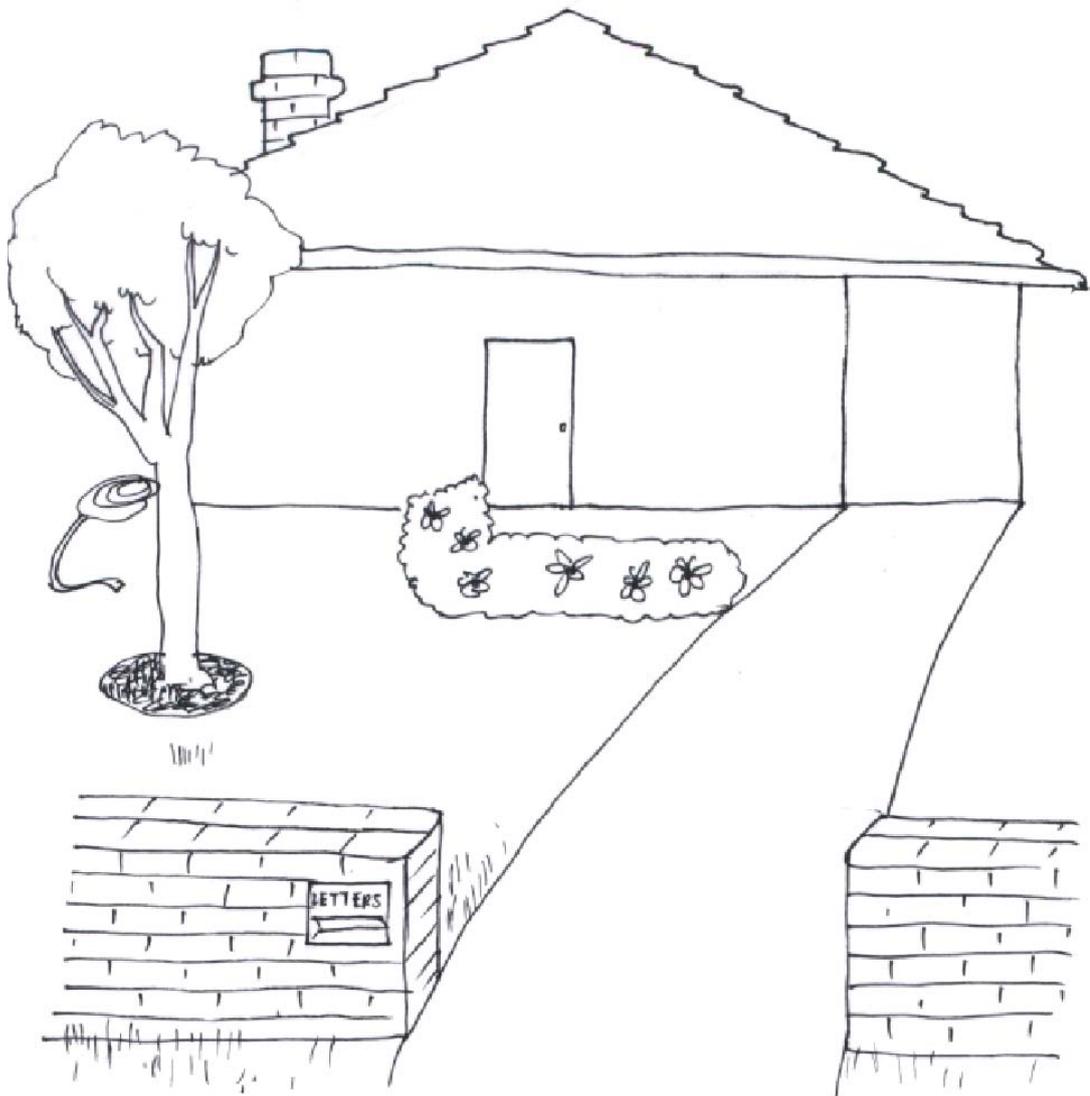


My Behaviour



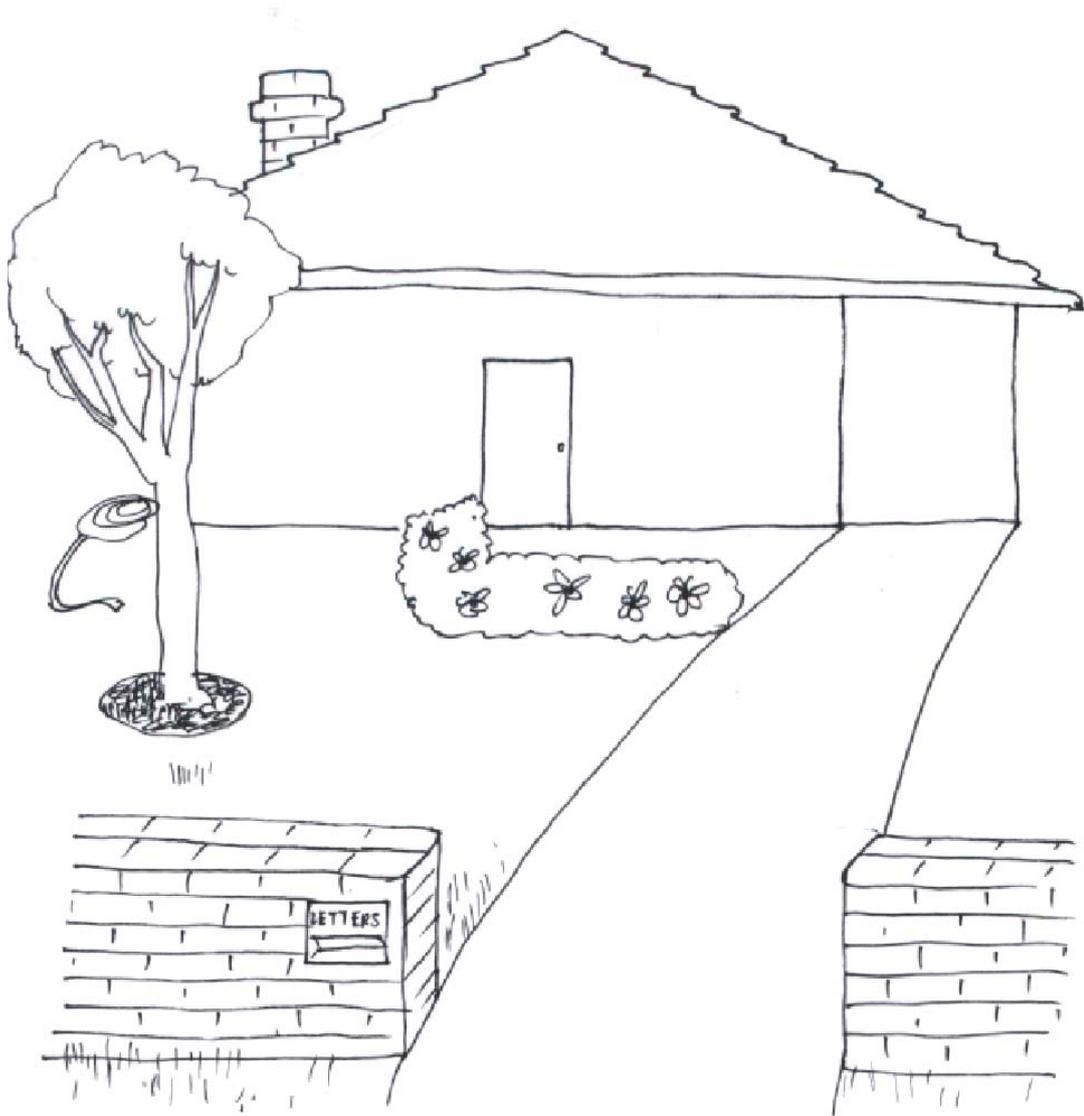
## Things I Can Do With My Sibling

Considering the strengths you have listed for your sibling above, list the things you can do with your sibling, at home and outside of your home. You can write the things you can do at home anywhere inside the house, and things you can do outside the home anywhere else on the page.



## Things I Can Enjoy Without My Sibling

While it's good to do things with your sibling, sometimes you may feel like you need to do something you enjoy without them. Brainstorm things that you can do without your sibling. Once again you can write the things you can do at home anywhere inside the house, and things you can do outside the home anywhere else on the page.





## Week 2

What did you learn in Week 2? \_\_\_\_\_

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---

How will this help you and/or your sibling? \_\_\_\_\_

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---

What activity/discussion did you enjoy the most and why? \_\_\_\_\_

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---

What activity/discussion did you enjoy the least and why? \_\_\_\_\_

---

---

---

What would you change about Week 2? \_\_\_\_\_

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---

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**Week 3:**

***Exploring and  
Communicating  
Feelings***

## Patchwork of Feelings

There are many different feelings siblings have, some positive and others more negative. Things siblings have said to us in the past include the feelings below. Often siblings don't express these feelings, especially at home for fear of worrying their parents even more, getting into trouble, or feeling guilty about feeling that way. It is important to remember that it's OK to have these feelings. Please highlight the feelings that you have about what it's like for you having a brother or sister with a disability **in the last week**.

|                   |                  |                  |                      |
|-------------------|------------------|------------------|----------------------|
| <i>Proud</i>      | <i>Worried</i>   | Content          | <i>Jealous</i>       |
| <b>Apologetic</b> | Loved            | <b>Angry</b>     | Concerned            |
| Frustrated        | Unloved          | Enraged          | Responsible          |
| Happy             | <b>Surprised</b> | <i>Different</i> | Guilty               |
| Secretive         | Special          | Resentful        | <b>Curious</b>       |
| Protective        | Confused         | <b>Important</b> | <i>Annoyed</i>       |
| Appreciated       | Lonely           | Sympathetic      | Sad                  |
| Embarrassed       | <i>Lucky</i>     | Afraid           | <i>Uncomfortable</i> |
| <b>Respected</b>  | Understood       | Sensitive        | <b>Supported</b>     |

Other: \_\_\_\_\_

## Hands of Support

The people in our lives form what we call a support network and can be another way of helping us cope. A network is the people in our lives that share both the good and bad times with us and can help us in some way when we are in a difficult situation. People in our network can help us in 5 different ways:

- *By giving us good information*
- *In a practical way such as helping us with difficult homework*
- *Providing friendship*
- *Helping us with our emotions by accepting and listening to us- Both the good and the not so good feelings we have talked about*
- *Protecting us in stressful situations*

Write the names of people who support you around the characters below.





## Other Supports

When things get really tough and you feel like there is no one in your support network who you can talk to, there are some community numbers to call:

KIDS HELP LINE      Free Call 1800 55 1800  
CRISIS CARE            9223 1111

There are also many websites set up for siblings. Some of them have sibling discussion groups where you can talk to other siblings from all over the world. They are all safe networks and all emails are monitored before being sent to the network.

The Sibling Project based in Adelaide has lots of information for siblings and a discussion group for younger and older siblings on their website at: [www.wch.sa.gov.au/sibling](http://www.wch.sa.gov.au/sibling)

The Sibling Support Project based in Seattle, Washington, has a website specifically for siblings of children with special needs. There is an internet discussion group for younger brothers and sisters (Sibkids) and older brothers and sisters (SibNet). You can register to the discussion group or find out more information about these at: [www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport).

Two other websites with helpful information include:

<http://www.sibspace.org/homeframe.html>  
<http://www.siblingsofautism.com/>

There are also some books, which have stories about what it is like for other siblings such as:

*Living with a brother or sister with special needs*: A book for sibs, 1996, (2nd edition, revised and expanded) by Donald Meyer and Patricia Vadasy (Seattle: University of Washington Press).

*Views from our shoes: Growing up with a brother or sister with special needs*, 1997 Don Meyer (ed.) (Bethesda, Maryland: Woodbine House)

*What about me? Growing up with a developmentally disabled sibling*, 1994, by B Siegel & S Silverstein (New York: Plenum Press)



## Week 3

What did you learn in Week 3? \_\_\_\_\_

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How will this help you and/or your sibling? \_\_\_\_\_

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What activity/discussion did you enjoy the most and why? \_\_\_\_\_

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What activity/discussion did you enjoy the least and why? \_\_\_\_\_

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What would you change about Week 3? \_\_\_\_\_

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**Week 4:**

***Coping Skills 1***

## The Problem-Solving Steps

**STEP 1** Define the Problem: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**STEP 2** What do you want to happen? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**STEP 3** Who will be affected (eg. family, friends, teachers)? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**STEP 4** What options do I have and what are the pluses and minuses for myself and others?

| Options | + | SELF | - | + | OTHERS |
|---------|---|------|---|---|--------|
| _____   |   |      |   |   |        |
| _____   |   |      |   |   |        |
| _____   |   |      |   |   |        |
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| _____   |   |      |   |   |        |
| _____   |   |      |   |   |        |
| _____   |   |      |   |   |        |

**STEP 5** What is the best option? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**STEP 6** What is my plan? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

***CHECK TO SEE IF THE PLAN HAS WORKED, IF NOT GO BACK TO STEP 4.  
IF IT WORKED MAKE SURE YOU REWARD YOURSELF!***



## Week 4

What did you learn in Week 4? \_\_\_\_\_

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How will this help you and/or your sibling? \_\_\_\_\_

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What activity/discussion did you enjoy the most and why? \_\_\_\_\_

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What activity/discussion did you enjoy the least and why? \_\_\_\_\_

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What would you change about Week 4? \_\_\_\_\_

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**Week 5:**

***Coping Skills 2***

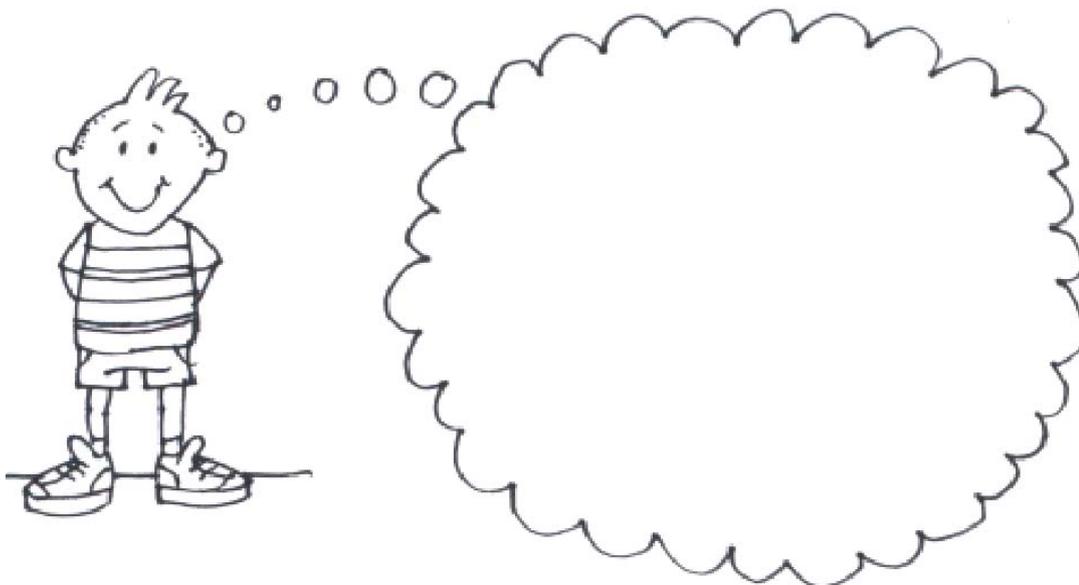
## Ways of Coping

As we have discussed having a brother or sister with a disability can be rewarding and fun, but sometimes it can also be frustrating. Often we will feel better by talking to our parents or friends about our worries and trying to solve the problem in the best way we can, but there will be times when none of this will work as the situation may seem out of our control.

### **Ways I Cope With Difficult Situations**



### **What Else Can I Do?**





## Deep Breathing Script

*I want you to sit in a comfortable position with your hands placed just over your tummies. I want you firstly to just take a normal breath in and out, in through your nose, out through your mouth. Look to see if your tummy is moving in and out, moving your hand with it. Feel your breath coming in like a wave, and going out like a crashing wave.*

Allow 1-2 mins for them to concentrate on their breathing.

*We are now going to do some deep breathing exercises. Most people only breath into their chest, but with deep breathing exercises we want to breath through your nose and pull your breaths right into your tummies for the count of four, then hold for four and breath out for four. You should be able to feel the breath coming into your tummy. Watch me.*

Demonstrate taking a deep breath.

*Sometimes it can be helpful to say something like "R-E-L-A-X" when you are breathing out or another word that makes you feel relaxed when you say it. OK, we'll now do the deep breathing exercise together. Hands on tummies and close your eyes just gently so nothing in the room can distract you. OK breath in pulling your breath all the way to your tummy, one, two, three, four, now hold, one, two, three, four, and out one, two, three, four.*

Repeat eight times. Then stop for 2 minutes and ask your partner how they feel. Explain that it feels a bit strange at first because you are getting a lot more oxygen to your brain, but it gets easier and that feeling subsides after lots of practice. Repeat the above sequence one more time. Ask your partner how they feel now- do they feel better than they did at the beginning? The middle? Congratulate them on a good job.



## **Progressive Muscle Relaxation Script**

*Gently and slowly close your eyes, now screw them up really tight, done that? now hold, a bit longer.....then relax them. Keep relaxing them..... Now scrunch them up again! And hold that,.....then let them go.....Feel how relaxed they are now.....Now we'll move on to your lips, press your lips together really tight, now hold that, then let them go.....Let them relax ..... Do that one more time, press them together.....hold.....now let them relax. Now smile as widely as you can....., then hold,.....then relax. Feel your mouth and lips feeling relaxed.....now one more smile, nice and big.....hold.....and then relax. Relax your whole face..... Now on to your shoulders, pull them right up to your ears as if you are trying to touch them.....hold that.....keep holding.....a bit more.....now gently let them go. Now push them up again and hold.....hold.....now relax. Feel your shoulders getting heavy and relaxed.....Notice how different they feel from a few minutes ago. Now with your arms by your sides, scrunch your hands and fingers up into a fist. Hold them.....a bit longer,,now.....let them go. Let them relax..... Now scrunch them up again, like you are holding something that you don't want to let go....., hold.....then relax. Now let your arms, hands and fingers go all loose like they are really heavy.....let them just relax.....Now pull in your tummy....., hold it tight and take a big breath..... then relax and breath out.....Notice your tummy feeling nice and relaxed. OK one more time, pull in your tummy tight, breathing in..... hold.....now let it go....., breathing out, notice how different it feels now. On to your legs now. Tense them up really tight, keeping them as straight as you can, pull your feet back as far as they'll go, curl your toes up.....hold now.... then let them go.... Let them relax now..... Once again, straighten your legs so they're really tight, pull your feet back, curl your toes right under those feet and breathing in....hold.....then breath out and let them all go loose. Notice how heavy and relaxed they feel now.....Now the last thing to do is tense up your whole body, from your eyes where we started, over your lips and mouth,.... shoulders .....fists.... stomach....legs, feet and toes so your whole body is now really stiff. Hold it..... Then let everything go loose and floppy. Feel your whole body relax. One more time.... tighten your whole body from your eyes to your toes... hold... hold a bit more..... Then relax...let your whole body go loose. Notice how different it feels now....everything feeling heavy, loose, more relaxed. Enjoy this new relaxed feeling. Remembering to control your breaths in, holding them, then breathing out. Are there any spots that are still a bit sore? Or is your whole body relaxed? Keep on feeling your whole body relaxed for a few moments now. Wait 1-2 minutes. OK, now slowly stretch out your arms and legs, keeping your eyes still closed. Then roll on your side, making sure you don't roll on to anyone next to you.*



## **Guided Imagery Script**

*OK, now get into your most comfortable position, gently close your eyes and listen to what I am saying. We are going to spend a few minutes thinking about a nice special place for yourselves. Somewhere where you feel totally relaxed, happy and safe. I want you to think about that special place in your head .... It might be at the beach, in the forest, on an island, at the park, on a farm or even in the middle of a big field. I want you to concentrate now and picture your special place in your head.....(Pause about 10 seconds). Now that you have a picture in your mind, I want you to look around your special place, what are the colours you see? (Pause about 10 seconds) What smells are there in the air? (Pause about 5 seconds) Feel the air on your skin in this special place (Pause about 5 seconds) and the ground underneath you (Pause about 10 seconds). Are there any sounds in your special place? (Pause about 5 seconds)..... Listen to them.....Feel yourself in this special place. (Pause for about 10 seconds). Feel how relaxed, happy and safe you feel in this special place. Let yourself look around your special place a bit more. (Pause for about 20 seconds). Let yourself run, skip, dance, walk, swim or fly around in this place. (Pause for about 20 seconds). Let that feeling of happiness and calm from your special place fall over you like a wave. Let your whole body feel relaxed and peaceful in this special place for a few minutes. Allow a minute to lie in this spot.*

*Now it's almost time to leave your special place. In your mind, I want you to walk around the area of your special place and wave. Wave to everything in your special place. Wave to any trees, birds, rivers, oceans, clouds and skys. (Pause for about 5 seconds). You will return to this special place again soon. (Pause for about 5 seconds). Now it's time to leave.....I want you to notice the sounds coming back to you from the sibling group. Feel what you are laying on. (Pause for about 5 seconds). Feel the air on your skin (Pause for about 5 seconds). Here the noises from outside. (Pause for about 5 seconds). Gently wiggle your fingers and your toes. Stretch your body out. S-t-r-e-t-ch, and now relax. Roll onto your left side and stretch a bit more. Roll onto your right side and stretch. Now as I begin to count, slowly begin to open your eyes. ...1...2...3...4...5. When you are ready stand up and stretch, up and up. Touch the roof, touch the side walls, now the ground. It's good to stretch. Well done everyone. How did that feel?*



**Week 5**

**What did you learn in Week 5?** \_\_\_\_\_

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**How will this help you and/or your sibling?** \_\_\_\_\_

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**What activity/discussion did you enjoy the most and why?** \_\_\_\_\_

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**What activity/discussion did you enjoy the least and why?** \_\_\_\_\_

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**What would you change about Week 5?** \_\_\_\_\_

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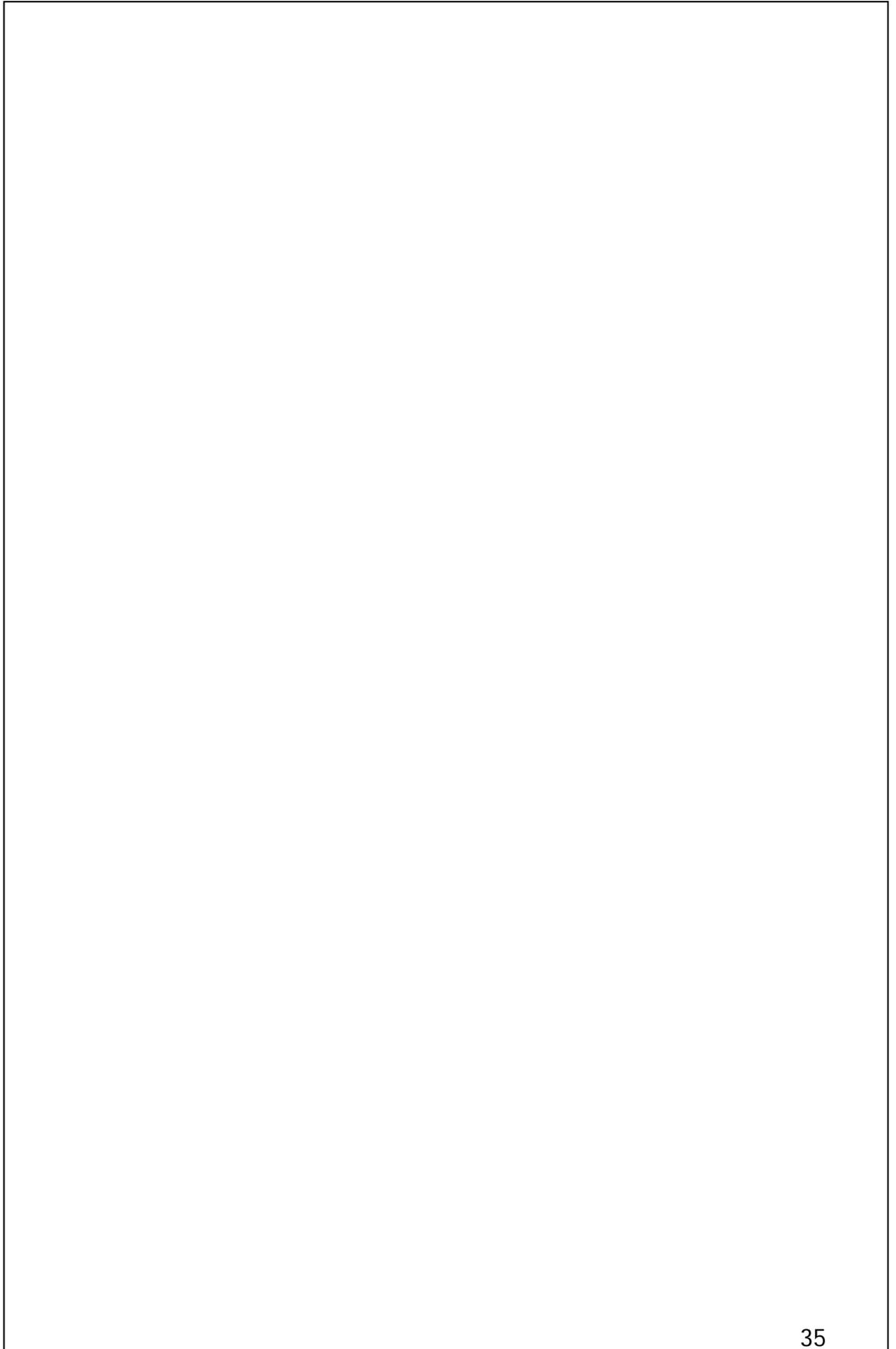
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**Week 6:**

***Finding Meaning***

## Picture of My Family

Draw picture of your family in the box below. Be as creative as you like!





## Finding Meaning

What is the most important thing you have learnt in the group sessions?

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What was your favourite group session and why? \_\_\_\_\_

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What was your least favourite group session and why? \_\_\_\_\_

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What has changed since you attended the group? \_\_\_\_\_

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## Week 6

What did you learn in Week 6? \_\_\_\_\_

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How will this help you and/or your sibling? \_\_\_\_\_

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What activity/discussion did you enjoy the most and why? \_\_\_\_\_

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What activity/discussion did you enjoy the least and why? \_\_\_\_\_

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What would you change about Week 6? \_\_\_\_\_

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Notes Page

