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My Sibling and I: Exploring the experiences and coping strategies of younger siblings  
of individuals with Down syndrome

A thesis presented in partial fulfilment of the requirements for the degree of

Masters of Arts

in

Psychology

at Massey University, Albany

New Zealand.

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2014



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## ABSTRACT

Down syndrome is a lifelong condition which impacts each family member in unique ways. Yet, with numerous studies focused on parental coping, little is known about the meanings siblings attach to the relationship they share. This study aims to investigate the personal experiences and coping strategies of younger siblings of individuals with Down syndrome. Three siblings aged between 17 and 22 years were interviewed to gather data on their experiences and coping strategies. The interviews were recorded and transcribed for analysis. Data was analysed using Thematic Analysis. Findings suggest four major themes and eight emotional states. The four themes identified are Blurred ordinal roles, Growth, Coping with society's perceptions and Future plans. The eight emotional states identified are feelings of Loss, Guilt, Uncertainty, Embarrassment, Protectiveness, Denial, Acceptance, Gratitude and Admiration. The results report an overall positive experience between siblings. Challenges related to the lack of public awareness, social stigma and functioning levels of siblings were raised. Siblings reportedly engaged in both, emotion-focused and problem-focused coping strategies. Variables such as family size and sibling's level of functioning were found to account for some of the differences across the case studies. The discussion provides suggestions on the practical application of findings, limitations and recommendations for future research.

## ACKNOWLEDGEMENTS

My sincere gratitude goes out to all the people who have helped me through the journey of completing this thesis:

Heartfelt thanks to Dr. Keith Tuffin who took on the role as my main supervisor for this research. His valuable comments, patience, expertise and guidance have benefitted me tremendously on this learning journey.

Dr. Tatiana Tairi, my co-supervisor, for her comments, encouragements and support.

Auckland Down Syndrome Association (ADSA) for their immense support in assisting with the advertisement and recruitment of participants. ADSA's support has contributed significantly to the success of this project.

My partner, who has accompanied me on this journey, thank you for being so caring and always encouraging me to achieve more. Thank you for staying up late with me as I study and providing me with opportunities to relief stress. Most of all, thank you for the cups of coffee, and your unwavering love, support and belief in me.

Friends and family, near and far, who have always encouraged and motivated me through the difficult parts of this journey. I am grateful for the support they have shown me and the words they have shared with me. I would not have reached this point without them.

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## CHAPTER 1 – INTRODUCTION

Disability, described as a “complex phenomenon” by the World Health Organization (WHO) is an overarching term that is used to refer to various types of impairments and restrictions in the social and physical interaction of an individual, with the environment (Kim & Lehto, 2013).

Living with a person with disability is a unique experience. Recent studies reveal that family members speak of the experience as having both personal gains and losses. The difference in appraisal of circumstances affects the way in which families perceive and report their experiences. Research that focuses on the personal perspectives of family members highlights the growing needs of the disability population. In the United States of America, one-third to two-thirds of the population that suffers from chronic psychiatric conditions are reportedly living with their family members (Leith & Stein, 2012). Depending on the disability type, individuals dependent on family members often require some support in carrying out daily living activities (Stalberg, Ekkerwals & Hultman, 2004). Among other things, caregiving responsibilities account for a significant portion of the long-term interactions family members share with individuals with special needs. The abundance of research aimed at documenting the well-being of caregivers is therefore no surprise. Emphasis is placed on the experiences of main caregivers, usually identified as mothers of individuals with disabilities. This limiting scope downplays the impact of disability on other members of the family, such as siblings (Leith & Stein, 2012).

Senner and Fish (2010), points out that the role of a sibling and the relationship they share is very different from parent-child relationships. Variables such as gender, age and role within the family are substantial factors that have been found to affect the

experiences of family members (Williams, Piamjariyakul, Graff, Stanton, Guthrie and Hafeman, 2010). The current literature relies heavily on the inputs of mothers and generalizes the experiences to other members of the family. Sibling relationship is unique and possibly outlives most other forms of relationships. Yet, there has been very limited research done to understand the first-hand experiences of siblings growing up with a sibling with disability (Senner & Fish, 2010).

There are many types of disabilities, each with its own unique characteristics and impacts. Therefore, disability research often involves classifications according to impairment type, severity and functioning levels. Down syndrome is diagnosed before or at birth, and may therefore impact families in different ways from disabilities that are diagnosed later on in life. Hodapp and Urbano (2007), argue that conditions that are diagnosed at birth or soon after, may result in greater access to resources and support services for parents. Also characterized by delays in meeting certain developmental milestones, siblings were found to play a key role in facilitating early learning in children with Down syndrome (Schuntermann, 2007). Hence, sibling relationship is often viewed as a valuable resource for parents coping with behavioural and developmental problems.

As Down syndrome is a lifelong genetic condition, it impacts families in different ways from treatable conditions such as depression, for example. Long-term caregiving responsibilities and unique behavioural and developmental challenges may influence a family's lifestyle and choices (Carr, 2005). The constant redefining of roles within the family due to lifelong caregiving plans is often viewed as a stressor, provoking extensive research documenting various coping strategies (Williams, Piamjariyakul, Graff, Stanton, Guthrie & Hafeman, 2010). Although a significant portion of studies view disability within a family as a stressor, it is crucial to note that there are growing

numbers of recent studies suggesting reciprocal relationships which account for many positive experiences as well (Benderix & Sivberg, 2007).

The bond siblings share experiences emotions ranging from rivalry to affection.

Sibling relationship is a unique relationship that is constantly being redefined as they grow and develop. Developmental researches propose that family relationships such as spousal and parent-child relationships form an important basis for children to define their relationship with their siblings (Fleitas, 2000).

Norwood (2013), illustrates the significant effects of family's appraisal of disabilities on the adaptive coping strategies adopted by siblings. Research aimed at documenting personal experiences are valuable as they provide an insight into the meanings people attach to relationships and experiences. The author suggests these meanings are often indicative of adjustments levels and overall quality of life of both, family members, as well as the disabled individual. Better adjustment levels are often outcomes of greater acceptance and adaptive coping strategies.

Many studies consistently report that the role of a sibling often evolves into a caregiver as parents grow older (Dyke, Mulroy & Lenord, 2008; Orsmond & Seltzer, 2007).

Wilson, McGillivray and Zetlin (1992), pointed out that most siblings of individuals with Down syndrome expressed their responsibility towards lifelong care for their siblings. Yet, Davys, Mitchell and Haigh (2010), highlight that little is done to understand the experiences and needs of siblings to ensure that they receive sufficient support when assuming the role of a caregiver in future. With the changing roles and life events, meanings people attach to their relationships and experiences are dynamic (Norwood, 2013). Understanding the experiences, expectations and hopes of siblings is the first step in ensuring a smooth transition for them.

Siblings may also view the way in which their parents treat them and their disabled sibling as biased (Mulroy, Robertson, Aiberti, Leonard & Bower 2008). This view may affect the way in which siblings view themselves as a valuable member of the family. Schuntermann (2007), illustrates sibling relationships using a dialectical framework by Bank and Khan. This framework places sibling relationship along a continuum with one extreme suggesting identification and the other, de-identification. The author argues that children's perception of their family's appraisal of the disability will affect the degree to which they identify with their siblings. Unlike parents, siblings may not be developmentally ready to comprehend disabilities and as such may have spent many years trying to cope with the differences between themselves and their siblings, as well as the differences in the way people treat them. Due to the unique relationship siblings share, many developmental experiences tend to be overlooked when research rely on indirect input from parents about siblings' experiences (Senner & Fish, 2010). The authors point out that the identification of sibling needs is a key step in working towards reducing risk factors and increasing protective factors for siblings. Factors such as age difference, gender and birth order are suggested to have impact on the relationship siblings share (Dyke, Mulroy & Lenord, 2008). By capturing the first-hand experiences of siblings, findings from this study will contribute significantly to the current sibling research and the overall understanding of their needs.



## 1.1 Aims of the Study

There is a range of research done on individuals with disabilities and their families. However, majority of the studies have focused on the needs, well-being and coping methods of parents. Siblings' voice was found to be excluded from most studies (Dyke, Mulroy & Leonard, 2008). Moreover, the limited disability studies that are conducted with siblings usually obtain inputs from older siblings, with a heavy focus on caregiving responsibilities. Davis (2010), suggests that age and birth-order play a significant role in the way siblings perceive their roles and relate with each other. The aim of this study is to examine the unique meaning of sibling relationships and exploring personal experiences and coping methods adopted by siblings from the perspective of younger siblings of individuals with Down syndrome. The main outcome of this research is to gain a better understanding of what it is like to have an older sibling with Down syndrome, the rewards and challenges non-disabled siblings face in their relationship as well as how they cope with their experiences. Findings from this study will contribute valuably to the existing sibling and disability literature. Results from this study will take us a step closer to understanding the needs of younger siblings of individuals with Down syndrome. This research can be used as a basis for future sibling researches targeted at informing professionals in the implementation and delivery of support services to caregivers of families with Down syndrome.

## 1.2 Organization of the Thesis

The literature review outlines previous disability and sibling research into Down syndrome (Chapter 2), Sibling relationship (Chapter 3), Development (Chapter 4), Caregiving (Chapter 5), and Coping (Chapter 6). Chapter 7 highlights the aims and rationale of this study. Chapter 8 will outline the methods used in the present study to gather qualitative data from younger siblings of individuals with Down syndrome. Themes derived from the analysis of data are presented in Chapter 9. These themes are further interpreted in connection to the available literature on sibling and disability research in Chapter 10. The strengths, limitations and possible application of the findings are also discussed in Chapter 10.

## Chapter 2 – DOWN SYNDROME

### 2.1 Overview

This chapter examines the current literature on Down syndrome, its characteristics, prevalence, prognosis and effects on individuals with Down syndrome. This chapter also divulges into the extent of impact, having a family member with Down syndrome, may have on other members of the family. Issues relating to resources and support services available within the community are further explored in this chapter, highlighting the importance of lifelong involvement of siblings.

## 2.2 Down syndrome

Down syndrome is a complex genetic disorder characterized by intellectual disability, malformation of various facial features, and a range of other physical and neurobiological impairments. Down syndrome results from the abnormal third copy of the human chromosome 21. It has been estimated that Down syndrome is responsible for almost 15% of the Intellectual Disability (ID) population, making it one of the most common genetic causes of cognitive impairments. Although most phenotypes and impairments are universal, the expression of deficits and its severity tend to vary across individuals. The prevalence of Down syndrome today is high, occurring at a ratio of 1:733 live births (Pinto & Schub, 2013). One of the major contributing factors is believed to be the rising age of expectant mothers. The risk of conceiving a child with Down syndrome increases dramatically from 1:385 after age 35, to 1:30 after age 45 (Ruparelia, Pearn & Mobley, 2013). Children born with Down syndrome are known to be more prone to developing a range of medical and mental conditions such as attention deficit hyperactivity disorder, autism, depression, obsessive-compulsive disorder, pneumonia, leukaemia as well as Alzheimer's disease. With the possibility of having to cope with a range of conditions, caring for an individual with Down syndrome will impact family members in various ways (Pinto & Schub, 2013).

Orfus and Howe (2008), argue that there is often a need for family members to make several adjustments in thoughts and behaviour in order to accommodate various aspects of the disability and function effectively as a system. Siblings, although often omitted from support services and research, were found to be equally impacted by the experience. Mulroy, Robertson, Aiberti, Leonard and Bower (2008), pointed out factors such as parental time constraints, parental emotion and the burden of helping out as some of the disadvantages of having a sibling with a disability, from parents'

perspectives. The study also suggests that parent-child relationship is affected by the birth order of the non-disabled siblings. Younger non-disabled siblings are born into family environments that are already coping with the demands of having a child with a disability. This may affect parent-child relationship in unique ways for younger non-disabled siblings compared to older ones.

This argument is further supported by Bendrix and Sivberg (2007), who reported siblings expressing negative feelings over the uneven attention and time they spend with their parents due to parents' caregiving responsibilities. Stigmatization associated with disabilities is another issue that is widely reported on. Abnormalities in certain facial features and lower intellectual functioning are some characteristics of Down syndrome that can result in social stigmatization. Mulroy, Robertson, Aiberti, Leonard and Bower (2008), argue that siblings often struggle with issues related to social stigma and biasness in the way their disabled siblings are treated by peers. This can further impact on daily routines, experiences and socialization opportunities of family members.

With the advancement in medical knowledge and resources, the lifespan of individuals with Down syndrome has increased significantly over the years. Long-term caregiving plans has therefore become a major area explored in research (Pinto & Schub, 2013). Although the literature highlights siblings as the natural choice for long-term caregiving, Leith and Stein (2012), suggest that the level of interaction and involvement among siblings is dynamic. Sibling involvement is found to be dependent on various factors such as the meanings they attach to their relationship, their perceived ability to cope as well as their perception of the level of support their parents require in handling caregiving responsibilities. Individual life events often dictate the

level of commitment exhibited by siblings in caring for the needs of their disabled siblings.

Being able to cope with the demands of the relationship is a valid issue that is central to most disability studies. There are formal and informal support system options within the community that families make use of when caring for the needs of a person with disabilities. Formal support services refer to governmental funded services that aim to provide financial, social and educational support to families. Informal support services include support from friends, family and the wider community. A negative correlation was found between the perceived usefulness, reliability and flexibility of support services, and stress levels reported by family members. This finding emphasises the importance of research that aims at exploring the needs of caregivers and tailoring support services to meet these needs in order to improve their well-being (Browne, 2010).

## 2.3 Chapter Summary

Down syndrome is a lifelong genetic condition that is responsible for a significant proportion of the Intellectually Disabled population. Characterized by distinct facial features and cognitive deficits, this chromosomal disorder may also be responsible for a range of additional health and mental health abnormalities. Families with children with Down syndrome are constantly coping with the demands and challenges of caring for the individual. As family resources are usually limited, non-disabled siblings may experience inequality in the distribution of resources such as quality time spent with parents. Currently, little is being done to assess the needs and experiences of siblings of individuals with Down syndrome. As possible future caregivers, there is a greater need for siblings to be included in support services that are extended out to parents. Access to support services was found to enhance the coping experiences of caregivers.

## Chapter 3 – SIBLING RELATIONSHIP

### 3.1 Overview

Siblings, due to their role and shared experiences, share a lifelong relationship that is unique within the family (Senner & Fish, 2010). Davis (2010), reports on the extent to which, disability among siblings impact on various aspects of the life of non-disabled siblings. The Wisconsin Longitudinal Lifespan study investigating sibling relationship, for instance, found that disability of a sibling affects areas such as the personality, well-being, relationship and family formation in the life of a non-disabled sibling. This is further supported by another study which highlights the impact of having a disabled sibling on the personal life choices non-disabled siblings make. This Study discussed the extent to which career choices, selection of a life partner, decisions on having children, future plans and attitudes towards disabilities is shaped and influenced by the experience of growing up with a sibling with disability (Davys, Mitchell & Haigh, 2010). Although generalized in many ways, every sibling relationship is unique and dependent on various factors that influences its course. Davys, Mitchell and Haigh (2010), suggest that the level of interaction and emotional attachment defines the characteristic of various types of relationships. Sibling relationship is commonly viewed as a long-term stable relationship that provides a reliable form of support in times of crisis. Nevertheless, the level of interaction and emotional attachment siblings share may vary in a cyclic pattern over the course of time (Leith & Stein, 2012). This chapter will divulge further into the significance of the relationship siblings share, investigating the variables that influence the emotional closeness and stability experienced in this relationship.



### 3.2 Importance of sibling relationship

As discussed earlier, sibling relationship forms a basic part of the support system people have. Having this bond becomes even more crucial and useful for families coping with individuals with disabilities (Davys, Mitchell & Haigh, 2010; Schuntermann, 2007). Other than support during times of crisis, sibling relationship also has a very valuable impact on many other day-to-day aspects of growing up. One major boon of this relationship is that it provides a safe platform for intellectual, physical, emotional and other key areas of development for children. Schuntermann (2007), points out behaviour imitation and modelling as evidence of early learning that takes place through sibling interactions. This view is further supported by Vygotsky's cultural-history theory of development. According to the theory, interaction between siblings who are functioning at different developmental stages often results in an environment that is conducive for guided and interactive learning (Klein, Fledman & Zarur, 2002). Although facilitating learning is a behaviour often displayed by older siblings, this may be exhibited by younger siblings if the older sibling fails to meet key developmental milestones due to a disability. Unruh (1992), talks about the important role siblings play in facilitating the achievements of key developmental milestones in the area of cognitive, social interactions, motor, visual-perception. The author also suggests that levels of confidence, motivation to engage in risk-taking behaviours, and learning to overcome challenges, can also be attributed to sibling interactions. Sibling interactions have been found to not only promote positive development but also increase occurrences of problematic behaviours. The author draws attention to behavioural issues experienced by families with children with disabilities. One of the major findings of the limited sibling studies available is that siblings often struggle to cope with problematic behaviours exhibited by the individual with special needs

(Senner & Fish, 2010). Siblings' well-being and socialization levels have been negatively associated with behavioural problems displayed by their disabled siblings (Schuntermann, 2007).

Mothers of children with disabilities consistently report behavioural issues as one of the major factors that affect caregiving, sibling interaction and parent-child interaction within the family. Parents highlight the significant impact behaviour has on stress levels, community involvement and the experiences of the non-disabled siblings (Davys, Mitchell & Haigh, 2010; Browne, 2010). Findings that support the extensive influence sibling relationship play in the learning and shaping of behaviour emphasises the need for extending resources and support services to siblings of children with special needs. This will not only address the need to teach children how to cope with their sibling's behavioural issues, but also how to reduce unwanted behaviours by actively modelling positive behaviours during interactions. As suggested by Senner and Fish (2010), research that aims at understanding the experiences of non-disabled siblings takes us a step closer to providing essential support for them. The author further states that support given to siblings, which increases their awareness on the needs of their disabled sibling, may bring about improvements in the relationship they share. The literature stresses the importance of explaining the disability to siblings in developmentally appropriate ways so as to increase awareness and understanding, therefore strengthening the sibling bond between them. This will also set a strong foundation for siblings who will transit from a sibling role to a caregiver's role when parents are unable to cope with the demands of caregiving because of age.

Brereton (2011), described an association between frequent interaction among siblings and positive outcomes in "fitting in" into society. Echoing similar findings, Griffiths and Sin (2013), describe the positive effects of socialization opportunities that siblings

create for their disabled siblings. Siblings can boost confidence and increase social and emotional competence of their disabled siblings through greater exposure to social situations and interactions.

Sibling relationship is argued to be often reciprocal in nature. Although many disability researches conducted previously report the negative impact of having a sibling with disability, current research show that siblings not only enhance the relationship by supporting the development of their disabled sibling, but also personally benefit and grow from the experience (Welch, Hatton, Emerson, Robertson, Cullins, Langer & Wells 2011). A study done on siblings of individuals with schizophrenia noted that patients perceive siblings as a crucial source of support despite the little attention this relationship is given in family-centred services (Stalberg, Ekkerwals & Hultman, 2004). Siblings report increased resilience, independence, gratitude and engagement in altruistic behaviours as some of the perks of growing with a sibling with disability (Fleitas, 2000). Growth in a relationship has been widely linked to adjustment. Adjustment is the process family members go through in understanding and accepting the disability. Families coping with a disability often report positive growth in terms of learning to manage expectations, raising awareness and advocating for the rights of people with special needs, being more open and accepting of differences and having a change in attitudes, values and beliefs (Degeneffe, Gagne & Tucker, 2013). Sibling studies propose that sibling adjustment levels, parental behaviour, parent-child relationships and the overall family adjustment levels are all interconnected. This is based on a theory that children often embrace the thoughts and behaviours of parents within a family setting (Schuntermann, 2007).

Family therapy is broadly based on the concept of a family functioning as a system.

The systems theory implies that the role of each member of the family impacts directly

or indirectly onto the roles of other members within the family (Davis, 2010).

According to (Fleitas,2000), having a family member with disability impacts the entire family in various areas of daily functioning. Family's priorities, daily living choices, future plans, communication networks, identities, values, sense of cohesion, needs and organizational structure will likely be affected (Degeneffe, Gagne & Tucker, 2013).

According to Attachment theory, children seek relationships with age-appropriate peers. Sibling relationship is one such bond that serves as a protective factor for children during their developmental years. The Colorado sibling study that used a continuum to describe the extent to which siblings identified with one another theorized that children, who were unable to form a positive relationship with their siblings, often shared close bonds with their friends. This pattern of forming attachments with others of similar age group has been described as "compensatory" and was found to be associated with increase in resilience and self-worth and decrease in anxiety and peer-victimization in the developing years (Schuntermann, 2007).

For a sibling, coping with the demands of having a disabled sibling can be complex. While parents were found to be able to accurately identify their child's understanding of the cause and definition of the disability their sibling has, they overestimated children's comprehension of the long and short term impact disabilities can have on families (Schuntermann, 2007). Given the lack of access to age-appropriate information on their sibling's condition, children may grow up with feelings of isolation and fear of the unknown. Lack of understanding about the disability may further reduce their ability to cope with social situations. Having access to accurate information and support has been associated with positive bonds between siblings. Age-appropriate support not only helps children identify with the needs of their siblings, but also empowers them with the knowledge to raise awareness, advocate for

their siblings and feel confident and safe in the relationships they build. Children have been found to experience distress and fear when they lack accurate information on their sibling's condition. Research shows that children struggle to cope with fears associated with contracting genetic conditions from their interactions with siblings. Being left out of most medical consultations and having little opportunities to interact with peers who may have similar experiences, children often try to guess information about their sibling's disability (Fleitas,2000).

With increasing emphasis on family involvement in community support programmes that target areas such as independent living and respite or psychiatric care, sibling relationship continues to play an important role in the treatment and care plans of individuals with disabilities. Siblings are often looked upon as the next best person after parents because of the degree of shared genetic, historical, cultural and social environment. Nevertheless, there are many variables that affect the type of relationship siblings share.

### 3.3 Variables that affect sibling relationship

Across most sibling research, age, more specifically the age gap between siblings, birth-order within the family, and gender are some variables that are consistently found to influence the interaction between siblings (Stalberg, Ekkerwals & Hultman, 2004; Unruh, 1992; Skotko, Levine & Goldstein, 2011; Carr, 2005). This is further supported by Wilson, MscGillivray and Zeflin (1992), who state that proximity of age, plays a part in defining the relationship siblings share. Another study suggests that family interactions, age and birth-order may be accountable for the differences in sibling experiences that are reported (Welch et.al, 2011).

Unruh (1992), talks about a comparison study on sibling relationship between siblings who have a disabled sibling and siblings who do not have a disabled sibling. The study investigated the extent to which disability affects adjustment levels of non-disabled siblings as well as the quality of relationship siblings share. An interesting finding suggesting that younger male siblings and older female siblings experience greater difficulties in psychological adjustment was documented. Furthermore, the study found that from the disability population, older female siblings tend to engage in more caregiving-related activities as compared to males. Males with disabled siblings were found to engage in similar levels of caregiving-related activities as females without disabled siblings, suggesting that roles and responsibilities of siblings may be defined through variables such as birth-order and gender.

Gender influences in sibling interaction was also documented by Cuskelly and Gunn (2006), who found that male siblings often engaged in more avoidant behaviours when interacting with a female sibling with Down syndrome. Unruh (1992), suggests that gender is also associated with sibling involvement in caregiving duties. Older female

siblings were found to be more involved as caregivers than their male counterparts. However, greater levels of engagement in caregiving were also associated with higher occurrences of negative interactions such as conflicts among siblings. Such conflicts may be attributed to role confusion when switching between the roles, responsibilities and identities of a sibling and a caregiver. The author suggests that in a caregiving situation, the dynamics of the relationship siblings share alters, as they are no longer interacting as peers. The phenomena of experiencing role dissonance can be magnified when a younger sibling takes on the role of a caregiver for an older sibling (Serdity & Burgman, 2012). When an individual is caught between two or more conflicting roles or cultures, they may experience identity role confusion and may therefore choose to reject or be rejected by one of the two conflicting roles (Bazuin-Yoder, 2011).

Age gap between siblings was found to be one of the factors determining the extent to which siblings engaged in conflicting roles as it will often determine the type of relationship siblings share while growing up. In a study reported by Unruh (1992), older female siblings as well as younger siblings with small age difference were found to be at higher risk of developing psychosocial problems in adjustment. The study also suggests that while engagement in caregiving responsibilities and taking on roles of a mentor or teacher is common in all sibling relationships, this behaviour usually declines with age. However, in a relationship where one sibling has a disability, engagement in this behaviour was found to increase with age. One possible explanation is the diminishing dependency normal siblings have on their brothers and sisters as they grow older. This is reversed in the presence of a disability as the ability gap between siblings is often observed to widen over time.

According to Aksoy and Bercinyildirim (2008), children tend to figure out their role with respect to their siblings so as to get an idea of the dynamics of the relationship. As

such, individuals growing up with a sibling with disability often figure out the differences in terms of strengths, weaknesses and other behavioural and functioning aspects. This, as suggested by the author, often results in “superiority” and “inferiority” roles siblings establish between themselves over time. This explains the protective behaviours exhibited by younger siblings of children with disabilities that are otherwise often exhibited by older siblings in a normal sibling relationship. Depending on the perception and attitudes siblings have toward the disability, they may also engage in excluding behaviours as a form of “superiority” role.

Emotional adjustment and coping behaviours impact significantly on the relationship siblings share. This hypothesis is supported by several other studies which explore the influence of age and birth-order on sibling adjustment. Skotko, Levine and Goldstein (2011), gathered that younger siblings experience feelings of loneliness and older siblings seem to exhibit more withdrawn behaviours from the family. However, other studies have been found to obtain mixed results on the significance of demographic variables on sibling adjustment (Skotko, Levine & Goldstein 2011). The difference in findings could be attributed to difference in the demographic and individual factors of participants, family factors, disability type as well as the method of data collection and analysis.

Supporting the systems theory of family functioning, several studies noted the possibility of parental adjustment as mediating factor in the psychosocial adjustment of siblings (Unruh, 1992; Aksoy & Bercinyildrim, 2008; Mulroy, Robertson, Aiberti, Leonard & Bower, 2008; Carr, 2005). Aksoy and Bercinyildrim (2008), proposed an association between the perceptions and attitudes a family has toward the disability, on the adaptation of siblings, the level of comprehension they have about the disability and the role of the siblings within the family. The author suggests that the type of



disability, given its unique characteristics and complexities, often impacts on the relationships within the family and their ability to cope.

### 3.4 Chapter Summary

The potential impact a bond shared between siblings can have on each of them has not been fully explored by researchers. Siblings spend the most amount of 'growing up time' together and will therefore influence each other's developments to great extents. Sibling relationship is seen as one of the longest and most stable relationship individuals can have in their life. In the case of long-term care plans for an individual with disability, a sibling is seen as a family's greatest resource. Although most siblings report challenges in coping with the behavioural characteristics of Down syndrome, the relationship is not without benefits. Reciprocity is one of the main characteristics of sibling relationship, with many siblings reporting personal growth and positive gains from interaction with their disabled sibling. Age, age gap, birth-order and gender are some of the factors that are found to affect the interaction, coping and caregiving experience of siblings. Sibling-friendly support services as well as family's perception of disability and their coping strategies have been associated with influencing the experience and coping style of non-disabled siblings.

## Chapter 4 Developmental Stages

### 4.1 Overview

A major part of growing up involves stages of emotional, physical, cognitive and other areas of development. Siblings learn and grow from shared experiences and often watch one another go through the various stages of development. The extent of influence siblings have on one another during the developmental years is emphasized when one of the siblings has a developmental disability.

Sibling relationship is a stable and long-lasting relationship. It evolves over time as individuals find themselves taking on different roles and responsibilities at different life stages. This chapter explores in greater depth, the impact developmental and life stages have on the relationship siblings of individuals with Down syndrome share over time. It will also examine the influence life stages have on the changing roles and interaction patterns of these siblings over the years.

## 4.2 Siblings and developmental milestones

Sibling literature and developmental theories emphasize the importance of sibling interaction in achieving developmental milestones. Tucker and Updegraff (2009), highlighted the differences in social experiences and learning environments parents and siblings create during the developmental years. Playing pretend with a parent, for instance, often involves undertaking very different roles, social scenarios and activities as compared to playing pretend with peers or siblings. This may be attributed to the fact that the adult is seen as an authority figure and may therefore fit into specific roles and scenarios during play. Children are more likely to engage in creative play involving 'grown-up roles' with their peers than with adults. Thus, although parent and sibling relationships stem from the same shared environment, they each play a distinct role in the development of a child through the unique learning opportunities they create for the child.

Interestingly, the author notes that interaction patterns among siblings were observed to change soon after a sibling took on the role of caregiving. During pretend play, these siblings were usually assigned similar roles to adults. This suggests that individual roles within a family play an important part in helping children establish meanings for relationships. In this study, siblings could no longer relate to their "caregiving siblings" as peers. This distinctively shows how roles of siblings can affect their relationship and interaction patterns.

Although peers seem to provide a similar developmental environment as siblings, Tucker and Updegraff (2009), argue that children were found to spend more time with their siblings as compared to their peers or parents after middle childhood. The study also suggests no significant differences in the amount of time siblings with or without

disabilities spend with their brother or sister. However, the activities they engage in may differ. For example, siblings of individuals with disabilities were more likely to spend a significant portion of time taking care of their sibling.

According to Erickson's Psychosocial Developmental Theory, middle childhood is a crucial stage where individuals are exploring their abilities, building their self-esteem and laying the foundations for identity formation (Waterman, 1982). Spending more time with siblings during this essential stage of exploration would mean that siblings play a significant role in boosting self-confidence and exploring self-identity.

### 4.3 Developmental stages and disability

Growing up with a disability and growing up with a sibling with disability each presents a very unique scenario. With majority of the sibling research focused on the experiences of the non-disabled sibling, research capturing the first-hand experiences of individuals with disabilities are far and few (Serdity & Burgman, 2012). This section will explore the impact disability has on the developmental experiences of both the individual with disability as well as their sibling. It also looks at how, and the extent to which, having a disability transforms the relationship siblings share as they go through different developmental stages.

Children with Down syndrome, although delayed in various aspects of development, do go through similar stages of development as their typically-developing peers. As such, the desire to have a social circle, make independent life choices and forming an individual identity is as significant for a child with Down syndrome, as their typically-developing siblings. As reported by Serdity and Burgman (2012), older siblings with disabilities were found to exhibit dominance in play and taking on the role of mentors and protectors to their younger siblings, rejecting stereotypical theories of dependency.

Refuting the underlying assumption that children growing up with a sibling with disability are disadvantaged, Welch et.al (2011), pointed out that the relationship they share is often reported as fair, with both parties contributing to and benefitting from the experience. Davys, Mitchell and Haigh (2011), found that most siblings do not report feeling left out or disadvantaged by the experience they have had in growing up with a sibling with disability. In fact, most siblings described the experience as enriching and fulfilling. A sibling expressed how the experience has helped shape her choices, identity and enhanced the relationships she shares with others. The experience

of growing up with a sibling with disability has been found to influence many developmental aspects of siblings; such as the choice of a romantic partner, making parenting decisions and career choices.

#### 4.4 Characteristics of disability

Aksoy and Bercinyildirim (2008), draw an association between the type of disability and the experiences reported by family members. The authors suggest that the lack of awareness and understanding of the complexities and issues surrounding a disability type results in a strain on the relationship of family members. This explains why greater stress levels are often reported by caregivers of patients with more complex conditions.

Severity of disability, on the other hand, was not found to affect the relationship of siblings as much as the characteristics of the disability. Siblings reported behaviour problems as one of the most difficult aspect of the disability they had to cope with while growing up. Disabilities that are associated with inappropriate social behaviours, challenging behaviours as well as lower independent functioning levels, was found to affect sibling relationships to a great extent (Wilson, McGillivray & Zetlin, 1992). According to Skotko, Levine and Goldstein (2011), the strain in relationship was often attributed to behaviours that are perceived as embarrassing especially for adolescent siblings. Further supporting this association, Wilson, McGillivray and Zetlin (1992), reported that adolescent siblings described inappropriate behaviours as the biggest cause of embarrassment and negative feelings. This, as suggested by the author, may be due to the fear of rejection by peers.

Cunningham (1996), reported an increase in behavioural problems exhibited by both the disabled adolescent and their non-disabled siblings during the teenage years. Orfus and Howe (2008), looked at coping strategies adopted by parents, and the stress appraisal and coping strategies of siblings of children with special needs. Sibling reports suggest that their social life is affected by the display of inappropriate social



behaviours of their disabled sibling, especially when the behaviour is displayed in front of their friends. Behavioural problems in disabled siblings were linked to parents' ineffectiveness in coping with the difference in the level of independence and socializing opportunities of their children.

Locus of control of siblings and their appraisal of situations have also been found to influence their transition in adulthood. Siblings who have to cope with behavioural issues often report feeling embarrassed, and torn between peer acceptance and standing up for their disabled siblings in social situations. Non-disclosure was also found to have a negative impact on the relationship siblings share with each other and their friends. Long term coping methods that involve social withdrawal can be unhealthy as it restricts the development of social identity and personality of individuals. This may have significant impact on the self-esteem and identity formation of siblings as peer acceptance does play a significant role in an adolescent's life (Tozer, Atkin & Wenham, 2013).

Identity, as argued by Bazuin-Yoder (2011), is formed through cultural affirmations, acceptance and assimilation. People often use others around them as a reference when incorporating beliefs and values. As such, identity formation may be viewed as a process of identifying with certain people and differentiating one's self from others. Nevertheless, there is always a process of trying to 'fit in' within society. As identified by Orfus and Howe (2008), non-disabled siblings often struggle to balance their identity and role as a sibling of an individual with a disability and peers because of a range of issues such as social stigma, feelings of embarrassment especially due to behavioural problems of their siblings and restricted opportunities to socialize due to responsibilities such as caregiving .

This argument is further supported by Mulroy, Robertson, Aiberti, Leonard and Bower (2008), who argue that factors such as “the lack of a ‘normal’ sibling relationship”, peer acceptance, having additional rules and routines to abide by in order to accommodate the needs of their disabled siblings, caregiving responsibilities, and having stressed parents affect the non-disabled sibling within the family. Negative emotions, low self-esteem and behavioural problems in siblings were identified as risk factors while communication within the family, family cohesion, support and resources were identified as protective factors for siblings (Williams, Piamjariyakul, Graff, Stanton, Guthrie & Hafeman, 2010).

Wilson, McGillivray and Zetlin (1992), suggest that individuals take time to adjust to and understand their siblings’ disability. Acceptance of a sibling’s disability may be influenced by personal experiences and life stages. This may be one reason for the cyclic pattern of changes in sibling interaction over time.

#### 4.5 Life stages and evolving roles of siblings

One variable that was found to be affecting the roles, responsibilities and experiences of siblings is the life stages of siblings (Davys, Mitchell & Haigh, 2011; Williams, Piamjariyakul, Graff, Stanton, Guthrie & Hafeman, 2010). Life experiences, circumstances and priorities that change over time may account for the changes in the dynamics of sibling relationships over the course of time. Siblings' perceptions of disabilities tend to change over the course of their lives, suggesting it may be influenced by the attitudes and beliefs of other family members as well as personal circumstances (Davys, Mitchell & Haigh, 2011).

The literature suggests that siblings of individuals with disability tend to provide greater support when parents are less able to (Stalberg, Ekkerwals & Hultman, 2004). This suggests that siblings progressively increase their involvement in caregiving responsibilities as parents grow older. The number of siblings available for sharing the responsibilities of this role impacts significantly on their roles and responsibilities they take up. However, studies suggest that there is usually one sibling that will have a higher level of involvement in the life of the disabled sibling (Davys, Mitchell & Haigh 2010).

Sibling relationship continues to play an important role in the well-being of individuals in their adulthood. Sibling interaction was found to be associated with positive progress in social integration and generally better outcomes in terms of independent functioning levels in adults with disabilities (Brereton, 2011). Lower independent functioning levels associated with disabilities may result in their inability to fully participate in shared activities and life events with their family. This exclusion may also impact negatively on the emotional bond siblings share.

The literature suggests that sibling relationship often go through a pattern of ups and downs through adulthood. Davys, Mitchell and Haigh (2010), argue that disability affects various aspects of a non-disabled sibling's life. Identity formation, life choices and future plans are some of the major areas of life that have been shown to be influenced by the disability of a sibling. Watzlawik and Clodius (2011), pointed out that siblings' relationship is influenced by their personal life stages. For instance, siblings were found to become less involved in each other's lives as they enter adulthood, a stage where relationships with their romantic partner and best friends supersedes sibling relationship. The literature suggests that, during this phase, a person's identity becomes less influenced and defined by their sibling and more defined by their partner and close circle of friends.

Mothers expressed worry about the transition their adult child makes from being a sibling to a caregiver for their adult child with Down syndrome (Carr, 2005). However, siblings were found to adjust well to the new role after some time. Although early research reported negative outcomes especially for older siblings, newer qualitative data indicate that siblings are able to embrace their new role over time.

Disability research suggests that the role of siblings, especially younger siblings, may evolve differently in families with individuals with disabilities. To illustrate the difference, Tucker and Updegraff (2009), draws a comparison between the role of parents in the Vygostky's Zone of Proximal Development and the role of older siblings. In Vygotsky's Zone of Proximal Development, parents play the role of a mentor in guiding children through new learning opportunities. Similarly, older siblings play an important role of facilitating the development of important skill sets of their younger brothers and sisters. The dynamics of sibling relationship changes slightly in families where the older child has a disability. Younger siblings experience

role reversal when they surpass their disabled siblings in developmental abilities. They are seen to play the role of the mentor, facilitating learning and development for their older siblings. However, unlike Vygotsky's theory where the role of the mentor reduces as the child gains greater competency, the opposite is seen in the case of a child with Down syndrome. The author states that in a regular sibling relationship, roles undertaken by the older and younger sibling becomes less defined, less hierarchical and more equal as they grow older. However, younger siblings of children with Down syndrome may notice that their abilities in various domains of development surpass their siblings' at a certain point. As they grow older, the gap between their abilities widens, and therefore, the need to guide their older sibling increases. Siblings reportedly engage in decision-making of major life events, assisting with legal and financial procedures, acting as a mediator, a friend, a support figure in times of crisis, a voice for the advocacy of rights and access to quality services for their disabled siblings (Davys, Mitchell & Haigh, 2010). These unique characteristics may influence the way in which younger siblings of individuals with Down syndrome perceive their relationship. The atypical ways in which siblings relate to and evolve in their relationship with a disabled sibling, supports the need for more research work aimed at understanding the bond they share.

#### 4.6 Chapter Summary

Individuals with Down syndrome generally go through similar stages of development but may spend a longer time achieving certain developmental milestones compared to others. Nevertheless, they reportedly abide by stereotypical birth-order roles within the family, suggesting that they are active contributors in the relationship. Siblings of individuals with Down syndrome consistently report a 'give-and-take' relationship with their sibling. Due to the proximity in age and the nature of the relationship, siblings tend to play a greater role in influencing developmental growth and outcomes as compared to other relationships. As a natural option for long-term caregiving, siblings find their role evolving from a sibling to a caregiver over time. Several factors, such as the comprehension of the characteristics of the disability, the behaviour and functioning level of the disabled sibling, as well as the perception of disability influences family coping. The life stages of siblings tend to influence the interaction patterns, the roles they adopt and the relationship they share over time.

## Chapter 5 CAREGIVING

### 5.1 Overview

A significant portion of disability research raise caregiving concerns and arrangements family make to accommodate the needs of their loved ones. Caregiving is one of the major responsibilities siblings expect to be entrusted with when parents grow old. This chapter will define caregiving and look at the common issues surrounding caregiving for a sibling with Down syndrome. Factors such as family size and expectations, which have been found to influence caregiving arrangements, will be examined in greater detail. This chapter will also review some of the key responsibilities and roles siblings play in caring for an individual with Down syndrome and how these roles influences the way they relate with one another.

## 5.2 Caregiving

The word 'Caregiving' is described as the act of caring for a person and is viewed as a fulfilment of duty toward relationships people share. Caregiving is a socially desirable act which is also socially expected. People are often expected to care for the needs of individuals who are not able to manage daily living activities independently due to illness, age or disability. With the advancement in healthcare facilities and services, the definition of caregiving has expanded to include various groups of dependent individuals as well as caregivers. The inclusion of special needs population and those suffering from chronic illnesses is recent as researches on caregiving were initially focused only on caring for the elderly. The responsibilities of caregiving duties typically fell on family members but have now broadened to include healthcare professionals such as doctors, nurses, rehabilitation service providers and medical social workers (Klum, 2012).

According to the New Zealand census data, more females than males take on caregiving responsibilities. This is consistent with findings from census worldwide, suggesting that the role of caregiving fits with traditional gender roles where females generally adopt roles related to caring and nurturing dependent individuals (Klum, 2012).

According to New Zealand's 2006 disability survey reports, statistics show that 90,000 children between the ages 0-14 years had some form of disability. Consistent to worldwide statistics and Australia's disability statistics, more males than females was reported to fall under this category. In these reports, having a disability was widely defined to include impairments that would last for at least 6 months or more. These impairments were broadly classified to encompass health problems, psychiatric or



psychological problems, chronic conditions, requiring special education, impairment in seeing, hearing, speech or intellectual functioning, requiring the use of assistive technologies and or other impairments that would interfere in the individual's independent daily functioning (Browne, 2010).

Difficulties in daily functioning are typically referred to as adaptive behaviour by clinicians. Deficits present in adaptive behaviour are one of the essential criteria for a diagnosis of Intellectual Disability (ID). Although clinicians often look at the concept of 'level of support' required by individuals to carry out their daily routines to determine the severity of impairment in independent functioning, researchers typically refer to it in terms of 'level of functioning'. The reason for variations in classification could be due to the difference in the nature of their role. Looking at the level of support an individual requires in carrying out everyday activities will allow clinicians to identify specific needs and therefore refer them to appropriate support services that will meet their individual needs. Level of functioning, on the other hand, has a better operational definition and will therefore ensure reliability of findings in research (Klein-Tasman & Janke, 2010).

Adaptive functioning is a broad concept encompassing various domains of functioning required for performing daily tasks. Social behaviour, conceptual skills such as language for communication, and practical behaviours such as self-care form the foundation set of skills required for independent functioning. Skill sets are often acquired over the years and competency in skills are usually judged in an age-appropriate manner. Developmental stages will therefore influence the definition of 'functioning level' (Klein-Tasman & Janke, 2010). Thus, the role a caregiver plays in supporting daily functioning will also depend on the age of both the caregiver and the person with disability (Klum, 2012).

For a young child, parents generally take on caregiving responsibilities, with a major focus on supporting the learning of conceptual and social skills such as literacy and communication. As the child grows older, the definition of adaptive functioning shifts to include greater expectations in the practical application of skills. Skills required for independent living such as self-care and work-related skills such as independent traveling will be given greater emphasis when determining level of support (Klein-Tasman & Janke, 2010).

Other than age, the nature of impairment will determine caregiving responsibilities (Klum, 2012). The ‘level of support’ concept helps to highlight areas in functioning that the individual require support in. It also helps to determine the extent of support required and therefore establishes the level of dependency individuals have on their caregiver (Klein-Tasman & Janke, 2010).

### 5.3 Caregiving in Down syndrome

Mothers of adult children with Down syndrome were found to experience a hike in stress levels when their child is dependent on them for daily care above the age of 35 years (Carr, 2005). This may be indicative of parent's lack of resources and ability to cater to the needs of a dependent child beyond a certain age. Another possible explanation could be the positive correlation between severity of disability and dependency levels. High levels of dependency in adulthood could be suggestive of severe disability and may pose greater challenges for caregivers. Caregiving demands can exceed a caregiver's ability to cope with it. This may cause personal and family distress and disruptions in other activities (Williams, Piamjariyakul, Graff, Stanton, Guthrie & Hafeman, 2010). Other studies have shown an association between caregivers' stress levels and social support provided by family members. In a study conducted with mothers of adult children with Down syndrome, 60% - 70% of mothers who were interviewed, expressed an expectation for siblings to take on caregiving responsibilities in the future. About half of them harbour expectations for siblings to continue staying together (Carr, 2005).

The experience of caring for an individual with Down syndrome is affected by many variables such as the level of disability, health status and behaviour of the individual (Davys, Mitchell & Haigh, 2010). Identifying some of these variables can be an important step towards understanding how they affect relationships, interaction patterns and meanings people attach to the experiences of caring for individuals with Down syndrome.

Behavioural issues such as dangerous behaviours and socially inappropriate behaviours may affect social acceptance and integration. Due to social stigma,

challenging behaviours may also act as a barrier for caregivers when seeking and receiving support from service providers. Other than constraints in resources such as time and money, behavioural problems were found to limit the social activities caregivers participate in (Browne, 2010). Socially inappropriate or dangerous behaviours may also interfere with daily activities such as shopping for groceries and family activities such as going on a vacation. Semi-structured interviews conducted with siblings of individuals with and without Autism revealed a positive correlation between behavioural issues and worries associated with future caregiving plans. Behavioural problems were also negatively associated with the social adjustment of these siblings (Benderix & Sivberg, 2007).

## 5.4 Chapter Summary

The definition of caregiving has expanded over time to include various types of caregivers and people requiring care. A general trend of more female than male caregivers is observed worldwide. Caregiving is seen as an evolving role due to the changes in the type and level of support caregivers render over time. Factors such as the age of both, the care giver and the receiver, and type of impairment will determine the role of the caregiver. Fulfilling the expectations of family and society, siblings of individuals with Down syndrome generally assume the role of caregiving over time. There are several barriers to caregiving, with challenging behaviour as one of the major ones that is consistently reported by caregivers. Coping with the role transition and demands of caregiving is one major area explored in disability research.

## Chapter 6 COPING

### 6.1 Overview

Caring for an individual may not be an entirely negative experience. Nevertheless, disability-related research are usually focused on issues related to caregiver's stress levels and maladaptive coping strategies, emphasizing the differences between families coping with disabilities and 'disability-free' families (Saloviita, Itälina & Leinonen, 2003). Family's appraisals of the stressor as well as assessment of available resources are found to influence the coping process. This chapter will examine the unique characteristics of different theories of coping. It will also review the various factors that have an effect on the coping strategies family members adopt over time.

## 6.2 Theoretical Background

Adjustment is the process of coping with stress. It is defined as the ability to respond to perceived stressful situations mentally, physically and socially. Adjustment patterns are often a reflection of the way in which people manage the perceived discrepancy between stressors and the available resources that will enable them to cope (Davis, 2010). The literature suggests several different models for coping, of which, the two-factor model is most commonly used.

The two-factor model proposes categorization of coping strategies as problem-focused and emotion-focused coping methods. Problem-focused coping involves strategies that are aimed at addressing the problematic issues directly. Adopting methods that target and reduce or eliminate the stress-causing element is indicative of positive coping.

Emotion-focused coping on the other hand is characterized by efforts to cope by changing the way one interprets and reacts to the stressor. Problem-focused coping is thought to be more adaptive than emotion-focused coping (Lees, 2009). Orsmond and Seltzer (2007), identified problem-focused coping strategies as one key factor associated with closer sibling bonds. However, people often switch between the two coping methods over time, depending on the situation, their perception of the stressor and their perceived ability to cope with it. Although widely used, the two-factor model is only one of the many coping models adopted by researchers. Another popular theory of coping uses the three-factor model. This model illustrates three types of coping methods, mainly cognitive coping, behavioural coping and avoidance (Lees, 2009).

Broad categorization of coping methods do not account for individual differences that may influence coping. The early findings of Lazarus and Eriksen's study on the impact of stress on skilled performance, highlights the role individual factors play in

determining coping outcomes. The study showed how different people who are exposed to similar stressors, may perceive the stressor differently and therefore have high, low or no response to it (Lees, 2009). Similarly, the literature highlights several factors that are found to influence siblings' adjustment to the experiences of growing up with a sibling with special needs.

While some studies suggest that demographic variables such as age, birth order and family size affect adjustment in siblings, other studies report little significance of such variables (Skotko, Levine & Goldstein, 2011). Hamama, Ronen and Feigin (2000), examined the adjustment of siblings of children diagnosed with cancer. In this study, siblings displaying signs of self-control were classified as coping positively while siblings exhibiting signs of anxiety and/or loneliness were viewed as emotionally distressed. The study found that age of siblings and duration of illness played a significant role in coping strategies adopted. Emotional distress was also found to be exhibited in different ways depending on the age of the sibling. Younger siblings expressed feelings of loneliness while older siblings were found to distant themselves from the family.

As suggested by Davys, Mitchell and Haigh (2010), interaction levels and emotional ties between siblings are often affected by life stages and personal life events. Coping strategies adopted by siblings can also be expected to change over time depending on factors such as age and life experiences. Problem-focused coping is an adaptive coping strategy that involves engaging in behaviours that targets problematic issues directly. Emotion- focused coping is a maladaptive coping strategy that involves avoidance or emotionalizing problematic issues (Orsmond & Seltzer, 2007). Adolescents were found to engage in emotion-focused coping in their early years, moving on to adopt problem-focused coping strategies later in adulthood. One explanation for this change



is the increased understanding of the disability and demands of caregiving responsibilities with age. Better understanding has been associated with higher levels of involvement in the relationship, and therefore better adjustment outcomes.

Family size, behavioural issues, age as well as coping strategies were also found to affect the quality of sibling relationship (Senner & Fish, 2010). Supporting general gender trends of coping, one study reported that sisters of females with Down syndrome typically engaged in emotion-focused coping instead of problem-focused coping (Orsmond & Seltzer, 2007). Support programmes that cater to the needs of siblings will increase their awareness on disability characteristics and equip them with resources that may aid coping and lead to better adjustment outcomes (Williams, Piamjariyakul, Graff, Stanton, Guthrie & Hafeman, 2010). In addition to age, siblings' adjustment levels were also found to be interrelated with family variables such as birth order, family size and the relationships between family members (Senner & Fish, 2010; Williams, Piamjariyakul, Graff, Stanton, Guthrie & Hafeman, 2010).

### 6.2.1 Role of perceptions & appraisal in coping

Disability studies consistently report the significant influence parents' appraisal and attitudes toward disabilities have on a sibling's perception of their brother or sister, therefore affecting the relationship siblings share (Unruh, 1992). Siblings' adaptation is largely affected by their understanding of the disability and its characteristics. Aksoy and Bercinyildirim (2008), found that families that have a better understanding of the complexities of the condition and the needs of the person with disability are able to cope in a more positive manner. Disability types that are less complex are also related to lower stress levels reported by family members. The study also suggests that a family's attitude is interrelated with the sibling's comprehension of the disability, and their adaptation to the role of a sibling to someone with disability. This concept of modelling attitudes is further supported by Mulroy, Robertson, Aiberti, Leonard and Bower (2008), who explain that siblings form an opinion about their brother or sister's condition through the experiences their parents create for them. These experiences are often biased by the parents' personal perspectives.

Studies suggesting normal family functioning levels in the presence of a disability such as Down syndrome, is indicative of cognitive coping which involves accepting and adapting to the needs of the disability. Positive reappraisal was highlighted as a key component to achieving acceptance. Methods of coping have been found to have a significant impact on the well-being of individuals. A caregiver's appraisal of their capacity to cope with caregiving responsibilities is usually associated with satisfaction levels and positive experiences (Klum, 2012).

### 6.2.2 Siblings' coping methods

There is no uniform measure of adjustment for siblings of individuals with disabilities due to the lack of research focusing specifically on adjustment. Generally, if the demands of the environment exceed the perceived resources such as support systems that are needed to manage the circumstances, adjustment difficulties may occur. In contrast, if there is congruence between the demands of the environment and the available resources, the sibling is more likely to cope positively and adjust well to the environment.

Studies previously available on sibling coping has largely focused on the negative experiences, suggesting development of 'at risk' behavioural problems. However, many recent research findings bring to light the positive outcomes that have been previously overlooked.

Harmer Cox and colleagues conducted a study with siblings of children with disability, aimed at investigating their coping strategies. Four main categories of coping were reported: Proactive, Interactive, Internally reactive and Avoidance. Majority of the siblings were found to engage in proactive coping, which involves independent problem-focused coping. Interactive coping also made use of problem-focused coping but by enlisting the help of others. Internally reactive resembled emotion-focused coping and non-active suggests avoidance as a form of coping. The findings of another study done with siblings of children with Attention Deficit Hyperactive Disorder (ADHD) were found to contradict findings from this study. Siblings of individuals with ADHD were reportedly found to engage in more avoidance coping which has been associated with maladaptive adjustment patterns (Davis, 2010).

A third study conducted with siblings of individuals diagnosed with Schizophrenia highlighted five major forms of coping styles adopted by siblings. Although most siblings were found to switch between styles, they were each found to have a predominant style of coping. Siblings were found to engage in avoidance, isolation, normalization, caregiving and grieving (Stalberg, Ekkerwals & Hultman, 2004).

In avoidance, siblings may be seen avoiding stressful situations cognitively, physically or both. This type of coping is hypothesized to protect siblings from negative emotions related to physical interaction with or thinking about issues involving the disabled sibling (Stalberg, Ekkerwals & Hultman, 2004).

Isolation results in disengagement from situations in a more passive way as compared to avoidance. Siblings who adopt isolation do so when negative emotions become too much to cope with. Removing themselves from the situation allows them to regain composure and carry on (Stalberg, Ekkerwals & Hultman, 2004).

Siblings that engage in normalization may seem to be in denial of the situation. Coping via normalization is used to deal with things that are viewed as beyond control or to fit in with the wider community. Issues related to social stigma, for instance, may cause siblings to adopt normalization as a coping strategy (Stalberg, Ekkerwals & Hultman, 2004).

Caregiving as a coping strategy involves channelling negative emotions in a positive manner. Siblings who adopted this method of coping reported strong involvement and support for their sibling, resulting in positive energy (Stalberg, Ekkerwals & Hultman, 2004).

Siblings who coped by grieving, often report similar desires to remain highly engaged in the lives of their siblings. However, unlike caregiving, siblings who cope by grieving were found to be more emotionally sensitive and passive in their coping methods (Stalberg, Ekkerwals & Hultman, 2004).

Many factors seem to have an effect on an individual's choice of coping method. The study also suggests that each coping style has an implication on family functioning (Davis,2010). Judging from the situations in which avoidant coping was reportedly used extensively, it is likely that siblings adopt this method of coping when they perceive a lack of control over the situation.

### 6.3 Coping as a family

Hodapp and Urbano (2007), suggest that conditions such as Down syndrome, which are diagnosed at birth or soon after, are related to better adjustment outcomes for families as compared to conditions diagnosed in later life. This could be attributed to better management of expectations from the onset, greater support that new parents receive from referrals to service providers as well as better prognosis linked with early engagement in intervention programmes.

Most siblings report positive adaptation to growing up with a sibling with disability. Although some report experiencing lack of attention by parents or increased pressure to achieve goals that their disabled siblings are not able to, a significant proportion of siblings indicated little difference compared to normal sibling relationships.

Coping with social situations is one of the consistently reported challenges by siblings. Social stigma, bullying, behavioural issues and coping with the lack of empathy and understanding others have for individuals with disabilities are some commonly reported problems siblings have to cope with (Davys, Mitchell & Haigh, 2010). Nevertheless, siblings report that these challenges have not restricted their normal childhood experiences and opportunities (Cuskelly & Gunn, 2006).

Siblings of individuals with hereditary conditions such as Schizophrenia and Down syndrome may also struggle to cope with the fear associated with the hereditary nature of the condition. Siblings express concern on issues related to pre-natal testing and caregiving. This underlying fear may also influence future decisions such as having children of their own (Stalberg, Ekkerwals & Hultman, 2004).

#### 6.4 Factors that influence coping in siblings

Further supporting the importance of coping in siblings, Davis (2010), suggests that insufficient attention has been given to siblings and their adaptation. Although research has shown that most siblings do not experience major adjustment difficulties, little has been done to explore the wider social context of sibling interaction in understanding the concept of coping.

According to Bronfenbrenner's Ecological Systems Theory, an individual's experience is influenced by the wider social context in which that individual functions in (Davis, 2010). With the advancement in healthcare services to include respite care and therapy services, caregiving duties are no longer limited to family members (Klum, 2012). Family, peers, and the wider community in which the individual is in constant interaction with, is responsible for the experiences of that individual. In coping however, the influences of these interactions are often overlooked and minimized. Environmental influences, parental adjustments levels and the overall family quality of life are key variables that have an impact on the coping levels of siblings (Davis, 2010).

Klum (2012), argues that coping should not only include caregiving duties, but should also account for the stress faced by siblings in taking over caregiving responsibilities and dealing with external agencies to assess support services. Benderix and Sivberg (2007), added that siblings often experience fear of not being able to provide quality care to their siblings when taking over caregiving responsibilities from their parents. This emphasizes the need for siblings to be included in support programmes and be given sufficient information and access to services that usually target parents. With insufficient knowledge, training and support, siblings are at risk of coping in

maladaptive manners, possibly leading to social withdrawal and burnout. This will in turn have an effect on the individual with disability (Klum, 2012).



## 6.5 Chapter Summary

Coping is an essential common part of the experience of families of individuals with special needs. Coping strategies of individuals within the family have found to be dependent on various factors such as the age and experience of that individual, the individual's appraisal of the situation, as well as their perception of the level of resources they have available to cope with the situation. Patterns of adjustments have been found to change over time, with some methods of coping proving to be more adaptive than others. Variables such as interactions and experiences within the wider community have also been found to affect individual's adoption of coping strategies.

## Chapter 7 THE PRESENT RESEARCH

### 7.1 Aims of Study

The broad aim of this study is therefore to explore what it is like growing up as a younger sibling to someone with Down syndrome. This study is exploratory and aims to investigate the experiences of younger siblings of individuals with Down syndrome. The limited literature on siblings' experiences is largely dependent on indirect data obtained from parents and teachers. Disability research aimed at understanding the benefits and challenges of living with an individual with disability, consistently target main caregivers, usually mothers. Although most studies report that siblings are likely to take on caregiving roles after parents are no longer able to, very little is being done to include siblings in research. Drawing on developmental theories, the current study aims at examining the relationship siblings share with their disabled sibling, the challenges and coping strategies they adopt to deal with those challenges.

By targeting younger siblings, this study seeks to explore, to some extent, the role of birth-order in influencing the relationship, challenges and coping strategies siblings adopt. This study will provide a platform for younger siblings to express their personal experiences that will contribute to the existing literature on sibling research. It may help to highlight the positive and negative personal experiences of siblings and commonalities in the way they cope with finding a balance between their role and identity within their families and their social identity.

## 7.2 Rationale and importance of Study

Siblings contribute significantly to almost all aspects of development by creating learning opportunities, sharing experiences and modelling behaviours. Children with developmental disabilities experience delay in achieving certain developmental milestones. They often require additional support and extensive facilitation in learning. When coping with a disability, the importance of the role a sibling plays is intensified. Different disability type and varying degrees of severity often bring about different issues, experiences and coping methods. There are several reasons for choosing Down syndrome for this research. Down syndrome is a genetic condition that is diagnosed in early childhood. It is present from birth, and not a condition that affects the individual at a later stage in life. When looking at family member's appraisal of life events, perception of the disability and coping strategies, it may make a difference if the child was born with a disability or developed a disability later on in life as it is assumed the latter will result in the family having to deal with 'loss' of, or adaptation to the changes in interaction with the individual. Moreover, it is not a treatable condition unlike depression, for example. Being a genetic condition, it also raises issues related to coping with fears of heritability in future. Characterized by certain facial features, Down syndrome is also a more 'visible' condition. This raises the point on having to cope with issues related to social stigmatization as well. Therefore, the needs and concerns of the family may be unique from other disability types.

Senner & Fish (2010), argue that the identification of sibling needs is a key step in working towards reducing risk factors and increasing protective factors to support siblings. By capturing the first-hand experiences of siblings, findings from this study will contribute significantly to the current sibling research and the overall

understanding of their experience. It will contribute in significant ways to the current literature as it aims to explore areas that have been overlooked in previous sibling studies.

## Chapter 8 METHOD

Semi-structured interview method was used for data-collection. An interview schedule was developed for the purpose of this research. The interview schedule comprised of five main open-ended questions. The questions targeted broad areas such as the overall sibling relationship shared between the two, benefits and challenges of the relationship, coping strategies as well as the overall experience of growing up with a sibling with Down syndrome. Additional relevant questions and probes were used as required during the interview for the elaboration and clarification of information shared by siblings during the interviews. Interviews were conducted in the privacy of the homes of participants. The interviews were audio-recorded and transcribed at a later date.

## 8.1 Participants

The criteria for participating were that the participants are between 16 and 30 years of age, living in the Auckland region, able to hold a conversation in English language, willing to commit for an hour for the interview and agree to have the interview audio recorded. They were given the option of having the Interview conducted at Massey University Albany campus, Auckland Down Syndrome Association or the privacy of their own homes.

The Auckland Down Syndrome Association (ADSA) assisted with the recruitment by contacting 131 families on their database who met the participation criteria. Families were notified of this Study through various channels such as via post, email and the ADSA Facebook page. Three siblings expressed interest in taking part in this Study. The age range of the three participants was between 17 and 22 years old. The gender make-up was two females and a single male sibling. Two of the three participants are migrant families living in New Zealand.

## 8.2 Interview Schedule

Data was gathered through semi-structured interviews with individual participants. The interview spanned across duration of between 30 to 60 minutes and consisted of the following five questions:

1. Describe your relationship with your sibling
2. Describe what it is like growing up as a younger sibling to a person with Down syndrome.
3. What is the best part of being a sibling to your older brother/sister?
4. What are some of the challenges in being a sibling to your older brother/sister?
5. How have you coped with these challenges?

## 8.3 Procedures

### 8.3.1 Ethics Committee

Ethical approval for this Study was sought from the Massey University's Human Ethics Committee under the Low Risk Category. A peer review evaluation of this Study judged this Study to be of low risk, consequently, not requiring a review by the University's Human Ethics Committees (see Appendix A). Assistance from the ADSA was adopted to fulfil three main requirements for this Study. ADSA agreed to assist in the advertisement and recruitment of participants, access to a suitable room for the interview, and referral to a registered counsellor as a safety net in the unfortunate event that a participant experiences distress as a result of participation in this Study (see Appendix B). The option of a free hotline for counselling services was also given to participants.



### 8.3.2 Informed Consent

Participants were informed of the nature of the Study, interview procedures, their involvement in the research and their rights as a participant in the information sheet (see Appendix C). This included rights to seek clarification on unclear information, rights to withdraw from the Study, confidentiality and security issues related to maintaining personal information and records for the purpose of this research, access to transcript of the interview and a summary of the research once the Study was completed. Participants were assumed to have given informed consent once they have read through the information sheet and signed the consent form (see Appendix C).

### 8.3.3 Confidentiality & Anonymity

Confidentiality and anonymity was maintained by assigning pseudonyms to participants and all mentioned names during the interview (e.g. their sibling with Down syndrome). The audio-recording of the interviews were deleted immediately after transcribing it. Personal information that may lead to identification within the Down Syndrome Association population, (e.g. exact family size, actual names and ages) have been omitted from the transcripts upon requests by some participants. All relevant documents were kept in a locked file cabinet at the researcher's home during the duration of the research. Following procedures, the documents will be stored in Massey University School of Psychology for seven years upon completion of the research study, after which, it will be destroyed.

#### 8.4 Data Collection

A copy of the Information sheet was sent to the Community Liaison Officer at ADSA informing her of the research procedures and criteria of participation for the purpose of recruitment of participants for this Study. A single soft copy and 132 hard copies of the advertisement were sent to the Community Liaison Officer of ADSA upon receiving Ethics approval for this research. Interested participants were told to respond to the advertisement via email that was specifically set-up for the purpose of this Study. Out of 131 potential families identified, only three individuals responded expressing interest of participation. The small number of respondents is not a surprise given that the research targeted a very specific group of individuals. A suitable time and place for the interview was arranged for with the three respondents. Communication between these three participants and the researcher majorly took place via email, text messages and post.

#### 8.4.1 Compensation

Participants were informed that they would receive a small gift of thanks in the form of an Events Cinema Movie Voucher for participation in this research. Participants received their vouchers via post after they had returned the amended copies of their interview transcripts and signed copy of the Transcript Release Authority Form (Appendix C).

## Chapter 9 RESULTS

Given the small number of participation, the following chapter presents the findings in the form of three individual case studies, highlighting the unique experiences of each individual. An overview of the findings obtained from the five main questions of the interview is presented. Data was analysed using Thematic Analysis, a method of analysing qualitative data that identifies and groups common ideas as themes. In order to spot emerging themes, transcribed interviews were first individually read to get an overview of the experiences shared. Emotional words, significant phrases and thoughts were then marked. The highlighted ideas were then examined in greater depth for its contextual meanings. Similar ideas across the three interviews were then extracted and grouped under a suitable theme that enveloped the meaning of that experience. Finally, the individual transcripts were read alongside the themes chosen to evaluate relevance and ensure that the experience is accurately captured and adequately represented. The analyses of data not only revealed the common themes but also highlighted the differences in experiences reported by the three individuals. Patterns of findings drawn from this study are further cross-examined with the literature for possible interpretations.

## 9.1 Overview

The analysis of data suggests four major themes that represent the general experiences of participants and eight sub-themes that describe the range of expressed emotions.

The four main themes identified are Blurred ordinal roles, Growth, Coping with society's perceptions and Future plans. These four themes accentuate the main ideas from the personal stories shared by all three siblings. There was a range of emotions expressed by siblings throughout their personal narrations. These emotions were categorized into eight distinct sub-themes that captured their individual experiences.

The eight sub-themes are feelings of Loss, Guilt, Uncertainty, Embarrassment, Worry, Denial, Acceptance, Gratitude and Admiration. This chapter will examine the four main themes in greater depth, outlining the eight sub-themes as they arise.

## 9.2 Case studies

### Jess

Jess lives with her family in New Zealand. She has an older brother, Max, who is diagnosed with Down syndrome, and other typically developing younger siblings. The age difference between Jess and Max is small, resulting in a close relationship. Jess shared that Max has a friendly disposition and enjoys meeting new people. Details of her exact family size, sibling age and gender have been excluded from this study upon her request for privacy.

### Karen

Karen and her family are originally from Croatia, and are now settled in New Zealand. Karen has an older brother, Dan, who has Down syndrome, and a typically developing younger sister. Karen reports a very close-knit relationship with her older sibling, family and extended family. Being an immigrant family, she constantly draws on the topic of always staying in touch and staying close to home, with the meaning of home being “where the rest of the family is”. She attributes family closeness to her brother’s condition, expressing feelings of gratitude for being able to make time for each other. Karen identified Dan as one of the main reasons for the strong bond her family shares. She mentioned that Down syndrome runs in her extended family, with another relative diagnosed with it. The condition is therefore well understood and accepted by family members. Dan is reportedly shy around new people and seldom communicates with unfamiliar people. He has an interest in music and often spends his free time singing and dancing. Karen mentioned that her family participates in regular family activities

that cater to the needs of Dan. Given that Karen has extended family back in Croatia, relocating is a valid option her family continues to consider for the future.

### Paul

Paul is the youngest member in his family. He has an older brother, Jon, who has Down syndrome, and other typically developing older siblings. Jon presents with speech difficulties and often relies on non-verbal methods such as gesturing, to communicate his needs. According to Paul, Jon is able to use single words for some commonly used words such as “goodbye” and “water”. With increased independence as he grew older, Jon is now able to help himself to the things he wants from around the house, reducing attempts to communicate his needs to family members. The age difference between the oldest sibling and Paul is significant. Paul is closer in age to Jon as compared to his other siblings. Paul attributes their close relationship to their small age gap. Paul and Jon regularly engage in many shared activities as a way of bonding.



### 9.2.1: Blurred Ordinal Role

Developmental studies suggest that birth order often set the stage for defining of roles and responsibilities within a family. Interaction patterns, expectations and responsibilities are some aspects of relationships that are influenced by the age of siblings. Participants in this study reported instances in their development when their role as a younger sibling was not clearly defined, and often overlapped with responsibilities of the older child. Blurred ordinal roles could be a result of overlapping of roles, the addition of new roles or the contradiction of roles. In this study, all three participants expressed blurring of lines between their expected role and their actual ordinal role within the family.

#### Jess

Being the middle child of the family, Jess plays the role of both the older sibling, as well as the younger sibling. Jess expresses instances when there is an expectation for her to play the role of the eldest sibling, by taking care of her older brother, Max. Although younger in age, siblings of children with disabilities may find themselves in situations where they are entrusted with responsibilities beyond their developmental abilities. This could be because they are thought to be more developmentally able, compared to their older siblings who may present with certain developmental delays. Jess's account of one such incident conveys her humorous experience of blurred ordinal roles.

*“I remember when I was about six years old, I started to take on responsibility for him. Once, we were at a mall, and mum asked me to watch over Max while she popped into*

*a shop quickly. Well, the funny thing was that he was fine, but I fell down the escalator!”*

She also shares developmental stories which highlight how developmental abilities often dictate responsibilities, resulting in contradiction of ordinal roles. Jess reports often engaging in shared activities and teasing behaviours with Max, which is typical of a sibling relationship. However, on hindsight, Jess noted that the bond they shared while growing up together, went through several changes. These changes were attributed to developmental stages of Jess, Max, and their other younger siblings. As Jess began to outperform Max, the contradiction of roles affected their interaction patterns. Describing it as an “Awkward stage”, Jess recalled how he brother began to relate lesser to her and more toward her younger siblings when he realised that she was starting to surpass his abilities. The drop in interaction was described by Jess as a phase of uncertainty and confusion, which passed with growing time.

*“there’s a certain part where I started to read better than him and started to talk better than him and I can beat him at Math skills...like we were really good friends when I was below him on educational level, but then when I started to surpass him, he didn’t tend to want to hang out with me so much...And then he would play with my younger sibling more.”*

Their relationship improved when Jess began to settle into playing the role of the “older sibling”. Jess also revealed her brother’s desire to reserve his spot as the eldest in the family.

*“so when I was a little bit older, 8, 9, I was the older one almost. But he wouldn’t like to hear me say that ...he really enjoys being the eldest in the family...and having all those privileges”.*

Jess described increased responsibilities at home and in caregiving as the main activities which have led to the blurring of lines between her role as an older and younger sibling to Max.

### Karen

Karen expressed her experiences of constantly switching between the roles of the younger and older sibling of Dan. In her sharing, she described her relationship with Dan as similar to any other sibling relationship. She also often compares their bond to the bond her friends have with their older sibling. Karen acknowledges her position within the family and expresses that her parents take on the main responsibilities of caring for Dan. Nevertheless, she does take on roles and responsibilities that are typical of an older sibling when relating with Dan, blurring the distinction between their ordinal positions.

She often looks out for her older brother and is quite protective of him, especially when he is in public and vulnerable to bullying. Karen also shares her experiences of being involved in some decision-making for Dan, advocating for his rights, organizing activities for him as well as instructing him to carry out independent daily activities such as cooking.

Although Karen relays her concerns for the future over the lack of independence her brother exhibits, she contradicts her feelings and seems comfortable with the dependency. Karen describes examples of instances when she finds it difficult to “let go” and struggles with the idea of Dan having “too much independence for his own

good". She conveys feelings of overprotectiveness and fear of independence as it seems to put her out of her comfort zone.

*"I think compared to friends that have got older brothers or sisters driving around and you got to worry about. It's quite scary. Whilst he is always here (laughs) and he is just singing every day... "*

*"...I still don't want to leave home...my brother, that's probably sort of the major thing that's holding me back from getting out..."*

*"I would worry about him working. He used to work at the video shop...the sort of worry as to what could happen when you are not around with him. You never know. You compare him with some of the other Down syndrome kids who are living by themselves, who are quite independent. I want him to have some sort of independence but not to the extent of...I think it's more me".*

## Paul

Paul, the youngest member of the family, described his relationship with his older brother as *"not the usual relationship I share with my other siblings"*. He expresses that he had always played the role of the older brother despite being younger. He attributes the blurred roles to the fact that for as far as he can remember, his abilities were often better than his brother's. Paul conveyed an underlying emotion of loss when he described his brother's inability to engage in the role of a mentor as an older sibling.

*"He is 2 years older than me but I will say that I have always looked at him as my younger brother because when my abilities and my intellectual abilities kind of*

*surpassed him, then that's when I have to take on the role of guiding him along instead of him guiding me".*

*"...the way he behaves and the way he did other things, I knew from a very young age that he was a lot different...There was never really a specific moment when I realized he was different. I kind of just grew up with him always being that way so it has always been there. I think from the earliest moment I can remember".*

Paul explains that the family tries to enhance the experience for his brother by actively involving him in as many shared activities as possible. Being the closest in age to his brother, Paul expresses his brother's keen interest in imitating his choice of activities, often regarding him as a role model.

*"He likes to play a lot of sports with me because I play a lot of sports... whenever I am doing something, he kind of want to follow me onto it. So even though I am younger, I am kind of like the older brother...in a way".*

Although Paul enjoys and appreciates the time spent engaging in sports with his brother, he expresses a sense of guilt in being able to carry out some activities that his brother is unable to. This feeling of guilt is intensified in instances when his brother expresses the desire to engage in an activity and fails to comprehend the reasons as to why he is not able to do so.

*"...it is also very difficult when there are certain things you want to do that you know he can't do, but he wants to do too. Like he wants to participate as well and you would give the world for him to be able to do it with you but things are just not meant to...That's probably the biggest challenge".*

### 9.2.2: Coping with Society's perceptions

One of the major challenges siblings report is coping with society's perceptions of individuals with disabilities, how they should be treated and common misconceptions on the experiences of siblings of individuals with disabilities.

Engaging in socially inappropriate behaviours, not abiding by social rules when out in public, coupled with the public's lacking of understanding and acceptance of differences, are some of the main reasons cited by siblings for feeling embarrassed when they are out with their disabled sibling. Having distinct facial features as a giveaway sign of a disability is another issue that siblings highlight as a challenge they have to cope with. Siblings express incidences stigmatization, unwelcomed stares and a constant worry about people taking advantage of their siblings as some of the main concerns they have when their sibling is out in public.

Jess

Jess points out that people's perception of how a person with disability should be treated is challenging for her and her brother as well. People's perceptions emphasize the difference between a person with and without disability, thus creating a barrier for an individual with disability to lead a normal life, be treated the same, and be given equal opportunities as others in society.

*"I guess one of the main challenges has been people's perceptions of how you should treat them. So when people see me teasing him, sometimes people get a little bit like almost angry or like surprised that you can tease someone with disability. That's been funny but also challenging because he is my brother. I am treating him like a normal*

*person...he likes to be normal and he likes to grow up as a normal person and not a disability”.*

Although Jess views one of her responsibilities as advocating for the rights of her brother and acting in his best interest, Jess also describes feelings of guilt for sometimes reacting to social situations in ways that are intended to save her from embarrassment instead of advocating for her brother.

*“...then I also want to think I want to protect myself from being too embarrassed and protect Jeff from being too humiliated...you get embarrassed because he doesn’t...so it is a weird balance between deciding what to do.”*

On a positive note, Jess realizes that overcoming these barriers has allowed her to accept her brother for what he is and appreciate the learning experiences.

*“If someone does something and it is in front of a lot of other people and you are really embarrassed by it, it’s a challenge. But then afterwards you can appreciate that ...your boundaries got stretched a little bit...I think the appreciation of it, the good thing comes afterwards, after you have learnt not to be so embarrassed about things like that”.*

Jess disagrees with the perception of society that all individuals with a sibling with disability have similar experiences, arguing that every child with Down syndrome is different and every family is different. This therefore creates a unique experience for every child with a sibling with Down syndrome. Speaking of Down syndrome support groups that aim to cater to the needs of siblings, Jess feels that they are unable to cater to specific needs of individuals.

*“I don’t really see the point in them because you can talk to people about it but everyone is so different...it’s like grouping up all New Zealand tourists that happen to be in Japan and saying “You people have lots in common, let’s make a group. But actually they are very different...”*

Jess feels that her family and siblings are better support resources for her when it comes to coping with issues related to her brother’s disability. She points out that even though the disability type may be similar across a number of people, the challenges, experiences and needs are often unique to each person. With a greater understanding of the specific needs, strengths and weaknesses her brother presents with, her family is a more effective support system than external agencies, for instance.

*“I think, one of the things that all families with a kid with Down syndrome in them are all so different. All kids with Down syndrome are different as well...coping for me has just been basically talking to my own siblings because I know they really know my brother very well and they know me really well. But I am not sure it will help me to talk to someone else with an older brother with Down syndrome...”*

Karen

Karen talks about stigmatization her mother had to endure after the birth of her brother due to the lack of public awareness on disabilities.

*“...with mum...having a kid with Down syndrome, they got shunted off...”*

She feels grateful for the learning and socializing opportunities that individuals with disabilities have access to today.



*“It is not as amazing as now, when they have like classes for them and you are learning new life skills and stuff.”*

However, she expresses the need for more inclusion and public understanding. Karen attributes people’s perceptions to their upbringing and personal experiences. She feels that her unique experiences have made her more accepting and open to diversity.

*“When I was younger and I didn’t know any better until people started looking at him funny at school...actually he got along with the school children and they got along with him quite well but you still get the odd adults staring and the then kids staring... it really hurts you more than it hurts him...the older people are sort of more sympathetic towards you than people my age who are like oh that’s cool you know, they are a bit different but...of course you still get the odd few who will like freak out... When you tell people like you have a brother with Down syndrome some of them .... They are feeling bad for you and it is not like that. It is like well you have got no idea...he has got special needs but he is not sort of you know...”*

Karen also displays feelings of protectiveness over her brother when dealing with social situations such as worrying about his safety when he is out working. One of the factors that she feels contributes to greater risk of social stigmatization, staring incidences and bullying of individuals with Down syndrome, is the distinct visible facial features that is characteristic of this disability type. Referring to it as “a giveaway sign of disability”, Karen feels that individuals with intellectual disability for instance, may not experience as much stigmatization due less visible signs of disability. Karen also expresses discomfort leaving him alone at home or allowing him to travel independently. Karen is aware and prepared for the impact this dependency may have on the future responsibilities of caregiving that she will have to cope with.

Unlike Jess, Karen copes by regularly talking to her best friend who also has an older sibling. She compares her relationship with her brother to her best friend's relationship with her older sibling. Karen seems to shield her younger sibling from worrying about issues related to her brother's disability and instead confides in, and draws support from her social circle. Karen is therefore careful in selecting her friends who are accepting of her brother. She seems to prefer to keep her friend circle small and intimate.

*"...you are my friend based on how you treat others...well you sort of get an idea of who you let into your life. That is why I have only a small circle of five main friends and then my family".*

*"my sister...I don't want her seeing me upset at all because she might worry..."*

#### Paul

Paul echoes Jess's thoughts, pointing out that the public's lack of awareness and flexibility has taught him to learn to be more accepting of his brother and others with disabilities. Paul describes some of the challenges he faces in interacting with his brother in public. He attributes unwelcomed stares and people's rigidity in accepting differences to their lack of awareness about disabilities.

*"A personal challenge for me is that it is very difficult to take him out in public and be able to sometimes handle him. A lot of people stare and it is difficult when a lot of other people are very unaware and very naïve about people with mental disabilities. It is difficult to handle him when people expect a lot more from a common human being".*

### 9.2.3: Growth

All participants shared positive experiences in terms of personal growth, of growing up with an older sibling with Down syndrome. Siblings consistently report cultivating positive traits such as patience, confidence and happiness from their older siblings, remarking that the experience has indeed made them a better person. Despite seeing themselves as taking on the role of the older sibling, all participants felt that their sibling had created many learning opportunities for them.

All siblings in this research demonstrated acceptance of their sibling's disabilities and mentioned that they have grown and adapted to the experience of it. They express several learning points from the experience, revealing that the relationship is reciprocal in nature.

#### Jess

Jess shares about her experience of being embarrassed by her sibling at times, especially when he engages in inappropriate social behaviours in front of others. Although embarrassing at that point in time, she views the experience as a positive one today. Jess attributes her increased threshold of embarrassment to her brother, and argues that this has indeed made her a more confident individual who is now more willing to take risks.

Jess expresses her admiration for her brother. She shares about her brother's friendly nature and confidence in striking conversations with people.

*“He has taught me a lot, like how to be confident and walk and be friendly to people. It's really interesting. It's always fun to watch him do it. He will walk up to anybody and say hi and how you doing. And that's been a good thing to learn from. Yea...and*

*he has introduced me to a lot of people like he would walk up to anyone that he sees on the streets so I have ended up meeting some celebrities and things like that.”*

### Karen

Karen thinks that the experience has made her more open to individual differences in society. She mentions that the experience has made her more accepting of others and better at relating to people. Karen sees herself as a better individual as she feels that she is more genuine in her relationships with others and is able to empathize with others. In addition to personal growth, Karen attributes her close bond with her friends and family to the experience of having a brother with special needs. She expresses being grateful for the strong support system and quality time her friends and family create for one another.

*“...if anything it has made us closer”.*

*“...it makes you a better person in the sense of how you look at people and how much patience you have for people as well... you don't know what people have gone through and you do put yourself in their shoes...”*

Karen also mentions feelings of admiration for her brother's pleasant personality. She recalls conversations her family has had about always seeing her brother happy, smiling and enjoying his music.

*“...little things like I have never seen him cry. He has always happy. We were just talking about it the other day like we have never seen him upset”.*

Karen compares her relationship with her brother with her friends' relationships with their siblings. She draws strengths from such comparisons and expresses positivity over the relationship.

*"...actually better than most siblings... we make time for one another and I think that's what keeps us all together".*

*"...they do hang out but it is not the sort of let's make time...we would take him out for a movie every holiday.... I think the best part of it is that it's keeping our family together".*

*"I have always been a very homely person. And I think it has a lot to do with growing up in a family with my brother...".*

#### Paul

Paul shared similar thoughts, saying that the experience has increased his awareness on the struggles people have to overcome to do something that others may take for granted. He implies feelings of gratitude in his sharing when he says that *"it has made me extremely aware that things don't come easy for everyone"*.

Paul feels that the experience has made him a better human being as he is now able to empathize with others and engage in perspective-taking. This, according to him, has enabled him to accept differences in people as well as to appreciate and be grateful for the smaller things in life.

#### 9.2.4 Future Plans

One of the main concerns of all participants is the uncertainty of the future. All three participants expressed different forms of coping for the challenges they face. The lack of concrete plans for the future may be due to the fact that the future seems distant with their parents still managing the bulk of the responsibilities. Siblings may also view the future as unpredictable due to possible major changes in their personal life such as having a life partner, a career and settling down. Having other siblings to share the responsibilities with is also another factor that seems to influence the stress and urgency of having a concrete future plan.

#### Jess

Jess mentions that she is not really worried about future plans as it is still something that is still quite a while away. Her parents are currently the main caregivers for her brother. Jess feels that when her parents are no longer able to provide care for him, she will not have to worry about taking the sole responsibility as she has other siblings who will be able to help out with the demands of caregiving.

*“...well I still have my siblings so I am not alone...we can do it together...”*

#### Paul

Paul, being the youngest member in his family, and having several other older siblings, expresses little worry about having a plan for the future. He describes his coping strategy as *“taking it day by day”*. Being the next oldest in the family and having

several other siblings, Jess hopes to share caregiving responsibilities with her other siblings. Paul however also briefly mentions that family size and gender of sibling are factors that influence coping. He feels it would be extremely difficult and stressful for families where the responsibility for future caregiving falls on their only other non-disabled child.

*“I can’t imagine what it would be like for families where there is only one other sibling to look after their sibling when their parents can’t do so... especially if it is a female sibling. Because I think females tend to bottle their feelings up more... so you don’t really know how they are coping themselves...”*

#### Karen

Karen on the other hand, feels the need to shield her only other younger sibling from the main responsibilities of caregiving. Her plan for the future is to assume the role of the main caregiver. She expresses the challenges and impact this decision will have on various aspects of her life such as choosing a life partner and settling down close to her family.

*“...my previous partner wanted to move to America... if I do meet someone, I would have to bring up the fact that look I would eventually have to look after my brother. And that’s why it is a big deal as well meeting someone and seeing how they react... in the sense of bringing that up, that is sort of an important thing.”*

Karen’s decision to make certain life choices based on the needs of her brother is contradictory to Paul’s view of the future. Paul indicates that his brother will have to fit into the life choices he and his siblings make in the future.

The difference in perceptions of the future and locus of control can be seen resulting in very different feelings associated with the future. Although all three siblings express feelings of uncertainty, Karen displayed the most signs of worry and avoidance. When unable to cope with the demands or worries about the future, Karen shows signs of denial and avoidance by “*sweeping it under the carpet*”. Karen mentions that her family avoids talking about future plans or feelings associated with caring for her brother.

*“You don’t want to think about it but you have to think about it. It is your brother. But thinking about anything like that sort of gets me upset... think I will deal with it as it comes because things are sort of fine at the moment ...Even my parents, they don’t sort of... we as a family don’t sort of talk about it as to what is next...I don’t think I do cope. I just sort of try and deal with it every day as it comes... On the outside I am fine but like when you start asking me questions then I am like no please don’t ask me that sort of things.”*

Knowing that Down syndrome runs in her family, Karen expresses some concern over the possibility of having her own children diagnosed with it in future. However, she was quick to add that she will be accepting of it.

*“What if I have a Down syndrome child...I will accept it. I am absolutely fine with it...but it’s just a thought”.*

Caregiving, as highlighted by findings from the literature, is often dependent on the level of support and dependency the person with the disability requires from the carer. Similarly, Paul feels that one of the major challenges he will have to cope with in the future is his brother’s inability to communicate his needs verbally. Karen feels that her



brother's high dependency and her family's protectiveness over him will prove to be a big challenge in the future when her parents are no longer able to care for his needs.

## Chapter 10 Discussion

### 10.1 Overview

The findings from the previous chapter will be discussed in further details in this chapter. The main ideas presented and its relevance to findings from the literature will be drawn in this chapter. Overall similarities, differences and variable that account for these patterns of results will also be discussed in this chapter.

## 10.2 Main themes

The patterns of results suggest more similarities than differences in the overall experiences of siblings in this Study. Specific differences in experiences and coping strategies can be accounted for by variables such as family's attitude towards disability, size of family and level of functioning or dependency of the individual with Down syndrome.

Aksoy and Bercinyildirim (2008), points out that, children often assume superiority and inferiority roles during developmental years according to the differences they perceive between their abilities and the abilities of others. This was evident in the personal accounts of all three participants, who mentioned experiencing blurred roles and responsibilities while growing up. Due to the nature of intellectual disabilities, developmental delays in certain abilities may result in younger siblings 'overtaking' and assuming superiority roles. Nevertheless, the notion that individuals with disabilities are dependent and inferior is not entirely true.

Reaffirming the findings of Seredit and Burgman (2012), study which argues that older siblings with disabilities are not always dependent individuals and were found to embrace the role of the older sibling by looking out for the younger ones, Jess noted his desire to be regarded as the eldest in the family.

Echoing findings from the literature which report reciprocal relationships of siblings of individuals with disabilities, data gathered from these 3 participants is indicative of benefits such as positive experiences and personal growth (Welch et.al, 2011).

Challenging beliefs that siblings of children with disabilities are often disadvantaged and 'at-risk' (Davys, Mitchell & Haigh, 2011), Paul states that although he makes conscious effort to select activities that he can enjoy with his brother, he has never

restricted himself from opportunities because of his brother's disability. On the contrary, he attributes his brother's increased social opportunities to his and his other siblings' beliefs of not having to confine and define themselves by a disability. This view is supported by Griffiths and Sin (2013) who suggests that siblings provide crucial socialization opportunities for one another during the developmental years.

Findings from this Study is also consistent with the literature which indicates that caregiving has an effect on life choices such as career and selection of life partner, appraisal of events and personal traits such as empathy (Davys, Mitchell & Haigh, 2011). Karen for instance, strongly feels that her brother's dependency on her and her family has affected some of her major decisions such as dating partners and relocation plans. She also suggests family upbringing as a crucial determining factor for the impact a disability has on members of the family, their coping strategies and future plans. This is in agreement with earlier research which states that the overall approach and attitude a family adopts affects the adjustment levels of siblings (Aksoy & Bercinyildirim, 2008).

Reports on social stigmatization and embarrassment, although largely documented as challenges in previous studies, siblings in this research discussed how this experience has enhanced their ability to engage in empathy and made them a better person.

Negative experiences have been found to be reappraised and reported as positive learning journeys. This is seen in the reports of greater acceptance and adjustment to their sibling's disabilities over time. Advocating for the rights of their siblings is seen as a result of increased consciousness to the unequal treatments faced by individuals with disabilities (Barr, McLeod & Daniel, 2008). The role of siblings as advocates was present in reports by all three participants involved in this Study.

Another consistent finding was that siblings felt there is a lack of social awareness and acceptance for individuals with disabilities. Participants highlight their struggles to cope with everyday activities that involve interactions with society. Siblings also struggle to cope with public misconceptions of their relationship and interaction patterns with their siblings. Attributing such misconceptions to society's lack of understanding and tendency to differentiate rather than integrate, siblings argue that there is a need for greater awareness on issues related to disabilities. One participant felt that having a disability such as Down syndrome, which is characterized by distinct facial features, heightens social discrimination and increases incidences of staring behaviours. Barr, McLeod and Daniel (2008), suggest that the effect of such negative behaviours is usually felt by non-disabled siblings as they are socially aware of the implied meanings behind these behaviours and feel rejected by society because of their relationship with the stigmatized individual. Advocacy for the rights of their disabled siblings may therefore be viewed as a way of coping with their own feelings of being rejected. Avoidance can thus be seen as an attempt to cope with the situation by de-identifying with the stigmatized individual in efforts to feel accepted.

Most siblings report adopting different coping strategies in different situations and across time. This shows that coping is seen as dynamic and no single method of coping was found to always work best. The developmental age of siblings, family size and appraisal of events were found to be some of the factors that accounted for the difference in coping methods.

Siblings were found to engage in both problem-focused as well as emotion-focused coping strategies. Emotion-focused coping was found to be used in situations that they felt little control over. Avoidance was found to be used in situations where siblings assessed themselves to have little or no resources to cope with the stressor but the need

for immediate coping is high. For instance, Jess was found to engage in avoidance when she found herself in embarrassing social situations as it allowed her fast escape from the issue. However, she would later switch to problem-focused coping by reviewing the problem and coming up with alternative solutions to it when she felt safer and better equipped to deal with the problem. Siblings also report avoidance when they were experiencing a unique problem for the first-time, were young in age, or did not want to discuss their worries with another individual due to lack of rapport, following family culture of not discussing certain topics, or protecting other members of the family from worrying about the stressor. One such example is Karen engaging in avoidance coping by “brushing her worries under the carpet” when she felt emotionally overwhelmed by the uncertainty of the future. Revealing that her family avoids talking about future plans, she feels that bringing it up for discussion may cause other members of the family to worry. She also expresses the desire to protect her younger sibling from responsibilities associated with caring for her older sibling. According to Davys, Mitchell and Haigh (2010), it is noted that one sibling usually takes on the bulk of the responsibilities and is seen as being the most involved in the life of the disabled sibling.

Problem-focused coping was most evident when coping to problems involved making use of resources and support systems that are available to them. Having other siblings and close friends to discuss worries and challenges with was found to be useful coping resources. Siblings report a preference of confiding in peers and other siblings over confiding in their parents or seeking support from external organizations. One of the reasons for this is that siblings felt that they are able to relate better to their peers and other siblings. Jess points out that the challenges and experiences are unique to each person. External support services are not able to fully comprehend or cater to specific

needs of each individual. She claims that growing up in a shared environment, her other siblings have better knowledge and are able to relate to the challenges of growing up as a sibling to her brother. Similarly, Paul argues that siblings spend the most time engaging in shared activities and experiences, and would likely be sharing future caregiving responsibilities, therefore, they make valuable support systems.

Karen however, felt that she relates better to her close circle of friends as she feels the need to protect her younger sibling from worrying about future caregiving responsibilities and ongoing worries she faces. Her account of having a small but close circle of friends and importance of having her future life partner to be accepting of her brother's disability is suggested by Barr, McLeod and Daniel (2008), to be an exhibition of a typical outcome of growing up as a sibling to a person with disabilities. Schuntermann (2007), draws attention to the possibility of siblings using peers as a compensatory relationship for fulfilling needs that a sibling is unable to. Having peers that siblings of children with disabilities can relate to is seen as a protective factor and adaptive coping strategy. Overall, siblings view brothers, sisters and close friends as reliable support pillars.

Exclusive to genetic-related conditions, one experience typically reported is the fear of having future children diagnosed with the same disorder. Stalberg, Ekkerwals and Hultman (2004) discuss worries siblings and family members have about hereditary nature of conditions. Karen expressed a similar concern as she discloses that Down syndrome is a disorder that runs in her family. However, she shares that having more than one member of the family with Down syndrome has actually helped with the coping, understanding and acceptance of the disorder. She feels that the experience of growing up with her older brother has allowed her to know what to expect if she were to have a child with Down syndrome in the future. As with coping, Orsmond and

Seltzer (2007), argue that a greater understanding and experience of a problem often leads to engagement in better coping strategies. This could be one of the reasons why siblings report switching coping methods with age and experience associated with the problems they face. Therefore, involvement in early intervention programmes that aim at educating siblings on what to expect and how to cope with certain behaviours and situations may help with sibling adaptation.



### 10.3 Limitations

One of the limitations of this research is the small number of participants. Patterns of findings should therefore be interpreted within specific contexts. However, due to the specific participant requirements for the nature of the study, a small number of participants were expected. Most previous researches on siblings with disabilities were conducted on older siblings. For a genetic condition such as Down syndrome, the chances of having a younger non-disabled sibling are slimmer for various reasons.

Having a child with a genetic disability may worry some parents on the possibility of having more children with similar genetic conditions. It may also be more likely for families who have a child with a disability to refrain from having more children due to the lack of resources such as time and money. Therefore, the vast research done on older siblings may be due to the availability of participants.

Given that the nature of this Study is exploratory, aiming to capture the experiences of a small and less frequently targeted group of individuals, the small number of participants is sufficient for the requirements of this Study. The first-hand interview style in which data was collected, allowed for sufficient in-depth information to be gathered despite having few participants. Although limited by the small number of participants, the data gathered from this Study provides a good starting point for future researches to build up upon.

A second limitation is that all participants were recruited from an organization that supported their needs. Families who already have access to support services for themselves and their child with the disability, may be coping better than those who have no access to such resources. Help seeking may be seen as strength in itself.

Therefore experiences reported by siblings may be biased and less representative of

other siblings of individuals with Down syndrome who have no access to support services.

A third limitation is the nature of this Study. Due to the sensitive nature of the topic discussed that required personal disclosure to a researcher who is a complete stranger, response bias is a possible drawback. As pointed out by Norwood (2013), a person who is viewed as an outsider may evoke feelings of high defence and possibilities of giving socially desirable responses, especially if the topic being reviewed is highly stigmatized. As a result of standing up for their disabled siblings and advocating for their rights, siblings may report biasness in their sharing. Socially desirable responses are expected in almost all situations whether data is collected via paper-pen method or face-face interview. However, in the face-face interview design, the interviewer is given an opportunity to build rapport with the participants. Knowing a little more about the qualifications of the interviewer, being able to ask questions and knowing who the information is being passed on to, provides context, credibility and some comfort to participants. Social desirable responses may therefore be reduced in the face-face interview design chosen for this Study.

A fourth limitation is the fact that this Study involved a single point of data collection. Siblings were involved in one interview on one particular occasion in their journey as a sibling. According to Norwood (2013), people go through reappraisals of events and often view their relationships in new light as they take on different roles and go through various life stages. Capturing the experiences at a certain point in time will not accurately represent the whole picture as sibling relationships are dynamic and long lasting.

#### 10.4 Implications and recommendations for future research

This research has vast clinical implications in the area of assessing needs and coping strategies of siblings. Previous researches suggest an over-emphasis on the needs of parents and older siblings. Being older, these siblings were often present throughout the experience, since the birth of their sibling with special needs. Younger siblings, however, are often born into families that have already established a routine for coping with the daily demands. They often have to try to make sense of and cope with developmental challenges that are unique given their young age and special circumstances. Findings from this research help to highlight these differences, providing valuable information on how birth order, age, family size and other developmental factors affect the experiences of individuals. This research provides parents, educators and practitioners who may be working with siblings of individuals with special needs, with some understanding of the possible risk and protective factors for younger siblings.

Studies targeting younger siblings can have implications on bigger areas of a child's development as well. From Bronfenbrenner's theory of impact the wider community can have on the child's development, it is essential for practitioners to identify key variables that may account for differences in coping methods adopted by younger siblings. Maladaptive patterns of coping may be addressed by teaching siblings how to identify stressors and cope with them more effectively. Siblings have been found to engage in trial and error method of coping. They can be given opportunities to practice problem-solving skills that will prepare them for better coping in future.

This study also highlighted the effect society's perceptions of disability has on the adjustment of younger siblings. Practitioners can judge adjustment levels of siblings

and encourage them to use support systems such as their friends, families and wider community to cope with the experience. Siblings can also be taught the role of appraisal in coping with stressors. Siblings can be encouraged to actively engage in reappraisal of negative situations to help them cope more adaptively.

As suggested by the literature, younger siblings, because of their developmental age, are often not given sufficient information to fully comprehend the impact of disabilities. Issues surrounding future care plans and fears of having their own children diagnosed with Down syndrome, for instance, should be addressed in a professional manner. Parents and practitioners should include younger siblings in their discussion about future plans. Siblings should be encouraged to voice their thoughts in a safe environment. Addressing these issues will allow siblings to feel better supported and prepared for the future.

With limited research targeting younger siblings of children with disabilities, a greater focus in this area will allow improvements in support services and policies surrounding issues of families and disabilities. Studies that have previously focused on the disability population have immensely narrowed in on caregiving experiences. There is very limited research focused on the meanings of the relationship families coping with disabilities share. Although challenging, it would also be interesting to examine the meaning of disability and family relationships from the perspective of the child with the disability. Through the biased lenses of the younger siblings, this study has managed to capture a glimpse of the way their disabled siblings view the relationship.

## Chapter 11 Conclusion

In conclusion, the overall experiences of younger siblings have been found to be positive, with most of them reporting a good and close relationship with their older sibling. Being a small-scaled research with limited number of participants, further research needs to be conducted to establish better understanding of the unique experiences of younger siblings. This Study has provided a good foundation for future research by highlighting valuable first-hand insights into the perspectives of a younger sibling.

By examining the roles and coping strategies adopted by younger siblings, this research has raised some important findings which support developmental theories. The lack of attention on younger siblings has resulted in research findings that are skewed, as many developmental theories on coping, identity formation and role of siblings are affected by the age and birth-order of siblings. This Study has raised interesting findings on ordinal roles of siblings, and how the adoption of coping strategies changes with age and experience. These valuable findings act as an important basis for future sibling research. These findings have useful implications for family and support services that cater to the needs of caregivers as it highlights the developmental differences between the needs of parents, older siblings and younger siblings of individuals with special needs.

In a nutshell, the research findings support various developmental psychology theories and add an interesting dimension to findings that have previously been obtained from older siblings and adult caregivers. Therefore, in addition to its contribution to the existing literature, by highlighting the important developmental needs of younger

siblings, findings from this research have useful practical implications for practitioners working with families of individuals with special needs.

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**MASSEY UNIVERSITY**  
TE KUNENGA KI PŪREHURUA

7 November 2013

Amarit Singh  
B1/9 The Avenue  
Albany  
AUCKLAND 0632

Dear Amarit

**Re: My Sibling and I: Exploring the Experiences and Coping Strategies of Younger Siblings with Down Syndrome**

Thank you for your Low Risk Notification which was received on 29 October 2013.

Your project has been recorded on the Low Risk Database which is reported in the Annual Report of the Massey University Human Ethics Committees.

The low risk notification for this project is valid for a maximum of three years.

Please notify me if situations subsequently occur which cause you to reconsider your initial ethical analysis that it is safe to proceed without approval by one of the University's Human Ethics Committees.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

**A reminder to include the following statement on all public documents:**

*"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.*

*If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Professor John O'Neill, Director (Research Ethics), telephone 06 350 5249, e-mail [humanethics@massey.ac.nz](mailto:humanethics@massey.ac.nz)".*

Please note that if a sponsoring organisation, funding authority or a journal in which you wish to publish requires evidence of committee approval (with an approval number), you will have to provide a full application to one of the University's Human Ethics Committees. You should also note that such an approval can only be provided prior to the commencement of the research.

Yours sincerely

John G O'Neill (Professor)  
Chair, Human Ethics Chairs' Committee and  
Director (Research Ethics)

cc Assoc Prof Keith Tuffin  
School of Psychology  
Wellington

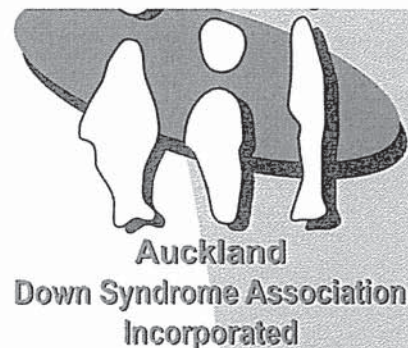
Assoc Prof Mandy Morgan, HoS  
School of Psychology  
PN320

Dr Tatiana Tairi  
School of Psychology  
Wellington

**Massey University Human Ethics Committee  
Accredited by the Health Research Council**

Research Ethics Office

Auckland, 22 October 2013



To: Amarit Kaur

RE: *Resesarch project "My Sibling and I: Exploring the experiences and coping strategies of younger siblings of individuals with Down syndrome."*

Dear Amarit

Auckland Down Syndrome Association is very happy to assist you with your research.

We can help you with:

- recruitment of participants by handing out the flyers and advertising for it on our website and Facebook page;
- the use of a room for the interview sessions.
- The help of a counsellor as a safety net for participants.

Clarifying point 3. We have found John Hibbs willing to step in the role of counsellor if needed ([www.johnhibbs.co.nz](http://www.johnhibbs.co.nz)).

Please let me know if there is anything else Auckland Down Syndrome Association can assist you with.

Kind regards

A handwritten signature in black ink, appearing to read "Christel van Baalen".

Christel van Baalen  
Community Liaison Officer





MASSEY UNIVERSITY  
COLLEGE OF HUMANITIES  
AND SOCIAL SCIENCES  
TE KURA PŪKENGĀ TANGĀTĀ

***My Sibling and I: Exploring the experiences and coping strategies of younger siblings of individuals with Down syndrome***

**INFORMATION SHEET**

**Researcher(s) Introduction**

Hi, my name is Amarti Kaur. I am currently a final year Masters of Arts student at Massey University Albany campus. This research project forms part of the requirement in completing my Masters degree in Psychology.

**Project Description and Invitation**

This research project aims at exploring the experiences of younger siblings of individuals with Down syndrome. If you do have an older sibling with Down syndrome and are interested in sharing your personal experiences you are invited to participate in this research study.

**Participant Identification and Recruitment**

Eligibility of participants will be determined through the following selection criteria:

- Have an older brother or sister with Down Syndrome
- Are between 16 and 30 years of age
- Currently live in Auckland
- Are available for approximately an hour
- Are fluent in English
- Agree to have your interview recorded

Participants will be compensated for their time and contribution in the form of a movie voucher.

**Project Procedures**

You will be involved in an hour long interview. The interview will take place either at the Auckland Down Syndrome Association, your home, or at Massey University Albany campus, whichever you deem convenient. You will be provided with information on support services which are available for you if you feel you require additional support after the interview.

**Data Management**

Data will be collected in the form of audio-recordings of the interview session. The recordings will be transcribed and a copy of the transcript will be sent to you for amendments. The amended copy of the transcript will be analysed for common themes.

All data collected will be stored in a safe and secure place. Following the University's guidelines, data collected will be destroyed seven years after the end of this project. All personal information will be kept highly confidential. Pseudonyms will be used in the documentation of information and privacy of all participants will be maintained at all times.

**Participant's Rights**

If you decide to participate, you have the right to:

- decline to answer any particular question
- withdraw from the study at any point in time
- ask any questions about the study at any time during participation
- be given a summary of the project findings when it is concluded
- ask for the recorder to be turned off at any time during the interview

**Project Contacts**

Researcher: Amarti Kaur  
Supervisors: Dr. Keith Tuffin, Dr. Tatiana Tairi

If you would like to seek more information about the project or express your interest in being a part of this project, please feel free to **contact the researcher at [researchdsnz@yahoo.com.sg](mailto:researchdsnz@yahoo.com.sg)**.

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Professor John O'Neil, Director (Research Ethics), telephone 06 350 5249, e-mail [humaneethics@massey.ac.nz](mailto:humaneethics@massey.ac.nz)





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AND SOCIAL SCIENCES  
TE KURA PUKENGA TANGATA

## Authority for the Release of Transcripts

### *My Sibling and I: Exploring the experiences and coping strategies of younger siblings of individuals with Down syndrome*

#### AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

**Signature:**

.....

**Date:**

.....

**Full Name - printed**

.....



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AND SOCIAL SCIENCES  
TE KURA PUKENGA TANGATA

*My Sibling and I: Exploring the experiences and coping strategies of younger siblings of individuals with Down syndrome*

**PARTICIPANT CONSENT FORM - INDIVIDUAL**

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/~~do not~~ agree to the interview being sound recorded.

I wish/~~do not~~ wish to have my recordings returned to me.

I agree/~~do not~~ agree for the researcher to use the original transcripts for data analysis if I fail to respond with the amendments after 21 days.

I agree to participate in this study under the conditions set out in the Information Sheet.

**Signature:**

.....

**Date:**

.....

**Full Name - printed**

.....