

Chapter 10

Brothers And Sisters With A Disability: Rewarding Or Challenging?

Jacqueline Small

Introduction

The recognition by the family that their child has an intellectual disability highlights the beginning of a journey that may bring both challenges and rewards. Siblings as well as parents face adjustment and adaptation to having a child with a disability in the family (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008). Increasingly over recent years, families, services, and the community have recognised, and to some degree, responded to the impact on a child of having a brother or sister with a disability in the family.

While in some cases, the whole family copes and manages very well, in others, the experiences and feelings aroused by the demands of caring for a child with a disability in the family may have adverse effects that may lead to significant mental health problems.

While it is unlikely that any one particular circumstance evokes either entirely positive or entirely negative experiences for the sibling, at times the negative experiences may overwhelm. One only need listen to the stories of siblings to start to develop some understanding of the impact of having a brother or sister with a significant developmental or intellectual disability. But what do we know of the experiences of siblings of children with a disability? What factors can improve adaptation to having a brother or sister with a disability? What current models of service are there to support siblings of children with a disability?

The Impact Of A Child With A Disability On Siblings

I felt completely isolated. I thought I couldn't share any of that part of my life with my friends. They didn't understand and I felt alienated from them. Other kids never had the same responsibility - Megan (Strohm, 2002, p.19).

Research has indicated that while the majority of siblings are well adjusted, a small number of siblings are at risk of developing significant adjustment difficulties (Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002) for reasons such as often missing out on parental time and attention, and being excluded from family discussion. There is greater recognition of the significant impact that siblings have on each other's development and the potential stress, and role confusion that siblings may experience when there is childhood disability in the family (Prizant, Meyer, & Lobato, 1997). However, there is some evidence that a sibling may experience advantage, in terms of both sibling relationships and of slightly better health and lessened depressive symptoms (Hodapp & Urbano, 2007).

Studies have investigated adjustment in siblings of children with particular diagnoses, such as autism (Sharpe & Rossiter, 2002; Rodriguez, Geffken, & Morgan, 1993; Fisman, Wolf, Ellison, Gillis, Freeman, & Szatmari, 1996) and Down Syndrome (DS) (Cuskelly & Gunn, 2006), and shown that maladjustment is not inevitable. Further, positive appraisals in multiple areas including parent perceptions of externalizing and internalizing behaviours, parent perceptions of sibling competence, and sibling perceptions of their own competence and self-worth have been demonstrated (Cuskelly & Gunn, 2006). However, studies have demonstrated elevated risk of internalising problems in siblings of children with autism when these are specifically sought.

In a study by Ross and Cuskelly (2006), 40% of non-disabled siblings had scores for internalising problems on the Child Behavior Checklist (Achenbach, 1991) that placed them in the borderline or clinical range. In another study, Orsmond and Seltzer (2007a) compared adult siblings of people with Down Syndrome or Autism

Spectrum Disorder (ASD). It was found that siblings of people with ASD had 'less contact with their brother or sister, reported lower levels of positive affect in their relationship, felt more pessimistic about their brother or sister's future, and were more likely to report that their relationships with their parents had been affected' (Orsmond & Seltzer, 2007a, p. 682).

Population based studies can overcome some selection biases associated with self referral. The parents of 186 Western Australian children with Down Syndrome and 141 Australian girls and women with Rett Syndrome were surveyed. The majority of parents reported both disadvantages and benefits for siblings, with some impact of place of residence, socio-economic status, and size of family. Major disadvantages for siblings from the study centred on parental and personal time constraints, relationships and socialising, restrictions, parental emotion, and the burden of helping. Major benefits were related to personality characteristics, for example, siblings were more accepting of differences, more caring and compassionate, and more mature (Mulroy et al., 2008).

Feelings Experienced By Siblings

Strohm (2002) identified that siblings may experience a variety of negative feelings including:

- Isolation e.g., no one to talk to, awareness that friends' lives are different, sense of being alone;
- Limited information about disability leads to opportunities to create fantasy explanations, limited use of diagnostic terms by parents, impact of parents grief;
- Fear of failure, disappointing the parents, adding to parents burden, may lead to becoming super helpful;

- Society's message of the child with a disability being 'special', made to feel that they are lucky to be normal;
- The impact of the reaction of others (e.g., pity, avoidance, too difficult to talk about, derogatory terms) may lead to overly protective behaviour towards the child with a disability but at same time experience feelings of conflicting loyalties;
- May turn own feelings inwards, particularly in the presence of high levels of parent distress, (Fisman et al., 1996);
- Sense of unfairness, life revolving around the child with special needs, always putting their needs first;
- Feeling abandoned or neglected;
- Frustrations at practical impact on family or other occasions;
- Impact on attachment as subsequent child with disability born who requires a lot of time and attention; and
- Confusion resulting from the message that it should be a positive experience.

Benderix and Sivberg (2007) conducted a thematic analysis of interviews with fourteen siblings of children with autism and intellectual disability. The analysis resulted in seven content categories including: precocious responsibility; feeling sorry; feeling exposed to frightening behaviour; empathetic feelings; hoping that a group home will be a relief; physical violence made siblings feel unsafe and anxious; and relations with friends were affected negatively. The conclusion was that these siblings' experiences revealed stressful life conditions.

An earlier study by Bagenholm and Gillberg (1991) involved interviewing sixty siblings and mothers of children with autism, intellectual disability and typically developing children. Siblings of children with a developmental disability, and especially

siblings of children with autism, were more concerned about the future than siblings of typically developing children. The siblings of children with autism and developmental disability also felt lonely more often and many of them had peer problems. They often regarded their siblings as a burden and tended to have only one sibling. Siblings often did not know why their brother or sister with disability was different from other children. There were more behaviour disturbances in the siblings of disabled children and mothers with a child with autism reported more 'stressful events'. There were no differences as regards the personality of the mothers and the self-concept of the children between the three groups (Bagenholm & Gillberg 1991).

Sibling Awareness Of Disability

He was playing with my hat and then went very quiet under the dinner table.

There was such a panic in the house - it was Christmas lunch. I never let my brother play with anything of mine after that - it was an obsession- in case it caused another seizure –Tara (Strohm, 2002, p. 22).

From a very young age, children may have different experiences associated with the disability of their brother or sister, with certain factors potentially leading to increased vulnerability among young siblings. Their egocentrism may lead to greater misunderstanding of their brother's or sister's condition and its impact on the family (Lobato, 1993). Parents may be particularly confused about how and when to share information about the child's condition with young siblings (Lobato, Kao, Engel, & Plante, 2000). In some cases, some of the very young siblings initially want to be similar, and attempt to imitate their brothers and sisters, particularly if he or she is also physically disabled. However, before they are 2 years old, children are able to recognise

that their older brothers and sisters are different, and often imitate the parents' behaviour towards the older child (Hames, 1998).

A longitudinal study by Hames (1998) described the changing understanding of younger siblings aged between 4 ½ months and 6 ½ years. Some siblings in the study copied their older sibling (e.g., responding to questions with 'ahah'; asking for splints for Christmas) while others wanted their older sibling to be like them. Some siblings copied their parents' behaviour towards their older brother or sister. Before the age of 2 years, some siblings had already stopped trying to persuade their brother or sister to be like themselves, for example, a 21 month old girl ceased setting a place at dinner for her sister who had a feeding tube. Hames (1998) found that by the age of 2 or 3 years, depending on the physical disabilities of the older child, siblings were no longer trying to be like their older brothers and sisters but more often like their parents. Siblings with brothers and sisters with profound learning and physical disabilities very quickly become aware that they were different (Hames, 1998).

It may not be possible to explain the abstract and less visible features of a disability to children under the age of 7 years, but by 11 years, children are able to understand the irrevocability of learning disabilities (Lewis, 1995). Therefore, clinicians should expand efforts to reach out to the siblings of children with disabilities, especially during adolescence, a stage of life during which the sibling may be particularly sensitive to the social stigma of a brother or sister's disability. It is suggested that supporting and educating siblings about mental illness and disability issues, may help them develop a deeper understanding of their brother or sister's experience, which in turn may foster a closer relationship (Greenberg, Seltzer, Orsmond, & Krauss, 1999).

Factors That Predict Sibling Involvement

There are a variety of factors that influence how much involvement a sibling may have in the life of their brother or sister with a disability. These factors may include,

- Expectations of parents that the sibling will be involved once they are no longer able to support their son or daughter with a disability (Orsmond & Seltzer, 2007b; Begun, 1989);
- The gender of the sibling, with sisters providing more emotional support than brothers (Greenberg et al., 1999);
- The relative age of the brother or sister with disability (Hodapp & Urbano, 2007; Rodriguez et al., 1993);
- The existence of behaviour problems (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997); and
- The demands and constraints of the adult years that involve responsibilities of work and parenting as well as the degree of closeness with the family of origin (Greenberg et al., 1999; Horwitz, Tessler, Fisher, & Gamache, 1992).

Another factor that pushes the sibling towards the caregiving role, is feeling closely connected with the family. Life course research suggests that continuity in family relationships over time, and thus the quality of family-of-origin relationships, forms a template for sibling relationships in adulthood (Cicirelli, 1995). Thus sibling involvement with the brother or sister with a disability may be sustained by family values that emphasise closeness across the generations and over time. Greenberg et al. (1999) suggested that if siblings were willing to take on at least some responsibility, the cost to the public would be reduced and the continuity of family-based support would be maintained.

Factors That Influence Sibling Response

When I was a kid I would be playing outside all day and when I got hurt or had my feelings hurt I felt like I couldn't go to my parents. They had so much work to do with my sister as it was, I took care of myself (Strohm, 2002, p. 33).

The well being of the sibling and the nature of their response to their brother or sister with a disability may also be influenced by 'external' factors, such as parents' marital satisfaction (Rodriguez et al., 1993). Although marital satisfaction, lack of parental depression, a cohesive family, and a warm non-conflictual sibling relationship were protective for some siblings, this has not been found to be a straight forward association. In a study by Fisman et al. (1996), it was the parent distress factor (composed of parental stress and depression scores) that mediated the relationship between quality of sibling adjustment and parent reports of internalising and externalising behaviour problems in the healthy (non-disabled) sibling. The findings stressed the importance of a transactional mechanism rather than identification of single risk or protective factors in predicting sibling adjustment (Fisman et al., 1996). Furthermore, when the level of environmental stress became overwhelming, factors that were previously operative no longer served to be protective (Garmezy, 1984).

Other researchers suggest that the family level of risk and resilience factors were better predictors of sibling adjustment than siblings' own experiences of stress and coping resources. This highlights the importance of familial and parental contributions to the sibling adjustment process. More specifically, socio-economic status, past attendance at a sibling support group, parent stress, family time and routines, family problem-solving and communication, and family hardiness, predicted sibling

adjustment difficulties. Finally, siblings' perceived intensity of daily uplifts significantly predicted sibling prosocial behaviour (Giallo & Gavidia-Payne, 2006).

While stress may be generated in part by the difficult temperament of the child with the disability, the sense of failure that is engendered in the caregiver (generally the mother), and the internal psychological distress may be the mechanisms connecting chronic family stress and behaviour problems of the healthy (non-disabled) sibling (Fisman et al., 1996). The variability in sibling outcomes may be related to a variety of potential moderating and mediating factors. These factors include genetic predispositions (Orsmond & Seltzer, 2007b) and the problem-solving approach used by the sibling, with the siblings being closer when the sibling used more problem focused coping strategies (Orsmond & Seltzer, 2007b). However, it is unlikely in healthy siblings of children with autism, that they convey specific characteristics related to the genetic risk associated with autism (Pilowsky, Yirmiya, Gross-Tsur, & Shalev, 2007).

Available Supports And Services

To know of other children my age who were “normal” but had disabled sibs, to be able to meet them, write to them, talk with tem, share with them, especially as we grew up and faced different challenges (Strohm, 2002, p. 181).

The perception by the sibling that they are well supported may serve to reduce the risk of internalising or externalising problems (Sharpe & Rossiter, 2002). Further, it is important to recognise positive family bonds, which encourage sustained involvement of family members in the care of adults with intellectual disability (Greenberg et al., 1999). Once adjustment disorders have been identified, counselling for the family and for siblings may be recommended to help them deal with their feelings and problems

(Benderix & Sivberg, 2007). However, several studies have shown that accessing professional support, such as medical and educational services, can have a negative impact on families of children with a disability (Giallo & Gavidia-Payne, 2006), perhaps underscoring the importance of parents sense of self efficacy and control.

Increasingly, services are responding to the growing awareness that supporting the family of a child with a disability is likely to contribute to improved quality of life for the person with a disability and reducing the risk factors for poor mental health outcomes. It is worthwhile engaging the sibling in discussions about the disability and respecting the difficulties they experience as well as the significant contributions they make towards their siblings welfare. Many organisations now offer siblings activities (for examples see, http://www.siblingsaustralia.org.au/ds_nsw.asp and also additional sources of support in Table 10.1) which include both recreational and fun elements in the program. Goals that are typical of the programs include connecting with other siblings, realising that their circumstances aren't unique, developing coping skills for stressful situations, and exploration of strengths of both the sibling and the child with a disability.

[Insert Table 10.1 here]

Of concern, however, is the limited analysis that participation in siblings groups has received. There is some evidence that participants enjoy and report benefit from attending group programs (D'Arcy, Flynn, McCarthy, O'Connor, & Tierney, 2005). Evidence also indicates that sibling knowledge, sibling sense of connectedness with other children in similar family circumstances, and sibling global functioning are

increased and that negative emotional or behavioural outcomes are unlikely (Lobato & Kao, 2005).

Conclusion

Given the reviewed research, professionals working with families need to consider the impact of disability on siblings as well as the identified child and their parents. Given that family contexts play a critical role in determining sibling adjustment difficulties, interventions that focus on supporting the whole family, in addition to directly supporting siblings, may be most effective. In particular, interventions aimed at helping parents to manage stress, improve parenting skills, strengthen family communication and problem-solving skills, as well as maintain family routines may be useful.

Strengthening sibling, parent and overall family functioning may also improve their ability to cope with and meet the needs of the person with a disability (Giallo & Gavidia-Payne, 2006).

Table 10.1***Sources Of Support For Siblings*****Details**

- Facebook for siblings of children with Down Syndrome (e.g., <http://www.dsansw.org.au/index.php?pg=444>),
- Email chat groups (e.g., http://www.siblingsaustralia.org.au/young_sibs.asp),
- Books (e.g., http://www.amazon.com/s/ref=nb_ss_b?url=search-alias%3Dstripbooks&field-keywords=siblings+disability&x=15&y=14),
- Movies (e.g., <http://www.theblackballoonmovie.com/>),
- Telephone helpline (e.g., <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=124&a=3989>),
- Camps (e.g., http://www.cooinda.org.au/Sibling_Activities.html), and
- Other online information (e.g., <http://www.youngcarers.net.au/>,
<http://www.reachout.com.au/default.asp?ti=2626>, ,
<http://www.healthinsite.gov.au/topics/Siblings>,
<http://www.acd.org.au/siblings/index.htm>, <http://www.youngcarersnsw.asn.au/>)