

Children and adolescents who are the siblings of children with intellectual disabilities or autism: Research evidence

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Summary

Parents of disabled children often report their worries about other children (siblings) within the family. There is a concern that perhaps siblings receive less attention and that some of the stresses and strains of raising a disabled child will also negatively affect siblings. In this evidence review, the highest quality evidence available that addresses the question of possible negative impact is described.

Currently, research evidence suggests that sibling psychological well-being and their relationships with their brother or sister with disabilities are relatively unaffected in a negative direction. There is evidence that a small number of siblings may be adversely affected. However, overall the research evidence focused on siblings is limited and there are considerable gaps with many unanswered questions. There is a clear need for a research prioritisation exercise involving all stakeholders with interests in siblings of disabled children.

Introduction

Direct (e.g., care demands, increased risk for mental health problems) and indirect (e.g., family poverty, reduced social networks) challenges face the families of children with intellectual disability (“learning disability” in the UK) and the families of children with autism spectrum disorder (ASD). Intellectual disability and ASD have sometimes been described together using the term “developmental disability”, and we will use that terminology in this document when referring to both of these groups of children together. When a research study focuses only on a specific group (e.g., siblings of children with autism), we will be clear about that.

From a broad family systems perspective, individual family members and family sub-systems are likely to be affected when there is a child with developmental disability within the household. Given the multiple challenges associated with raising children with developmental disability, an assumption might be that the impacts will be negative. Thus, parents or siblings in families of children with developmental disability may themselves experience more problems, or various family sub-systems might be affected. For example, there has been considerable interest in the relationship between parents in families of children with developmental disability including rates of separation and divorce. Similarly, the relationships between siblings may be affected when one of the young people has a developmental disability.

In a 2012 position paper, the *Families Special Interest Research Group* of the *International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD)* concluded that there was strong evidence that parents (especially mothers) of children with developmental disability are at increased risk for stress and mental health problems compared to parents who do not have a child with developmental disability. The *IASSIDD* review of research also included a very brief conclusion in relation to siblings, stating that there was evidence of both negative and positive impact and that the overall negative outcomes for siblings as a group may be minimal.

Since the *IASSIDD* 2012 position paper, there have been a number of new large scale research studies on siblings of disabled children published. In addition, a more detailed description of the current state of the research evidence is needed to inform families, support organisations, and policy makers. Therefore, the purpose of the present document is to provide an overview of the research evidence with a special focus on siblings of children with developmental disability. We also focus on research from Western nations, since the intention is to inform the work of Sibs, the UK charity for siblings of disabled people, and other UK organisations.

It is also important to point out that this evidence review is not “systematic”, and so we are not reviewing all evidence published and trying to describe what the evidence says overall. Instead, the focus is on larger scale and more recent research studies and an attempt to give a broad flavour of the research about siblings. Therefore, the review is more of an overview of sibling research drawing on the experience of an expert in the field.

An overview of the research evidence on siblings

Three broad areas of research have been carried out and published with a focus on siblings of children with developmental disability. The first area addresses the question of whether there is evidence for negative (or indeed positive) effects on the psychological and social well-being of siblings when they have a brother or sister with developmental disability. The second area addresses the impact on the quality of the relationship between siblings. Finally, researchers have carried out a number of in-depth studies in which they have interviewed siblings about their experiences and attempted to describe what things are like for the siblings themselves.

1. Are siblings at risk for more psychological or social problems?

The vast majority of sibling research studies have examined whether siblings of disabled children are at risk for increased problems. Two important aspects of research design are needed to be able to answer this question. The first is that a comparison with young people who are not siblings of disabled children is needed. Second, because there are many factors that might influence young peoples’ experience of psychological or social problems generally (e.g., their age, sex, and socioeconomic circumstances) these other variables need to be accounted for in some way. We can then have more confidence that any differences found are indeed related to having a disabled brother or sister and not related to some other factor.

An early comprehensive summary and meta-analysis of research studies including groups of siblings of children with intellectual disability and comparison groups, concluded that there was only a very small negative effect on psychological and social problems for siblings (Rossiter & Sharpe, 2001). This conclusion reflected the fact that some studies found increased problems for siblings, some found no differences, and still others found that siblings had fewer problems than other young people. It is also hard to draw firm conclusions about the evidence when many studies are small in size, and also the siblings that are included may not be representative of all siblings of disabled children. This latter point is about various biases that might occur when selecting samples of young people to study. For example, recruiting siblings via parent support organisations or through clinical or social services might mean that those with the most problems are most likely to take part. Alternatively, it could be that siblings with the fewest problems are the most willing to take part in research. Either way, the sample studied would then not be representative of the whole population of siblings of disabled children.

Two recent large scale studies, both from the USA, have addressed some of the limitations of existing research. Neely-Barnes and Graff (2011) analysed data from the US National Health Interview Survey that contains data on nearly 10,000 children. Just over 4,000 children of 4 years of age and older were selected from this database because they had a sibling, and within this group 373 had a disabled sibling (all disabilities were included not just developmental disabilities). The researchers also controlled for 12 variables that might have influenced outcomes (e.g., deprivation experienced by families) when comparing the siblings of disabled children to the rest of the siblings in the survey sample. The siblings of disabled children were reported by their parents to have more mental health problems, to use more mental health services, and their overall difficulties were rated as more severe. These differences between the groups, however, were very small in size thus generally supporting the conclusions of earlier research.

In the second recent large scale study, Goudie et al. (2013) analysed data from the US Medical Expenditure Panel Survey and again focused on families where there were at least two children in the family and where at least one of the children was not disabled. Disability was broadly defined (again, not just developmental disability), and based on parent report. There were 245 siblings of disabled children compared to 6,564 siblings of children with no disability. Overall, again after controlling for other potentially important variables, siblings of disabled children were almost three times more likely (2.77 times more likely) to have significant levels of problems in interpersonal relationships, their psychological well-being, school performance, or use of leisure time (as reported by parents) compared to other siblings. Focusing in on more detail, mental health problems were again more common in the siblings of disabled children (unhappy/sad 1.58 times more likely; nervous/afraid 1.89 times more likely), as were interpersonal problems (relationship problems with parents, siblings, and other people 1.55 to 2.23 times more likely). Interestingly, parents also reported that siblings of disabled children were more likely to have problems with their behaviour at school (1.84 times more likely) and problems completing their schoolwork (1.74 times more likely).

The conclusions of these two studies might seem to be somewhat at odds with each other. However, they rely on quite different data from parents about siblings and also have a different approach to analysis. In the Neely-Barnes and Graff study, mean (or average) scores on questionnaires about siblings of disabled children were compared as a group. Overall, there were only small differences in the overall level of problems between the two groups of siblings. In the Goudie et al. study, the focus was on children scoring above a certain level on each measure. So, the Goudie et al. data focus on how the groups of siblings compare in terms of whether they have particularly worrying levels of problems. Although there is not yet enough research to be clear about these findings, it may be that overall the risk of increased problems

for siblings of disabled children is small but the numbers with more concerning levels of problems are higher when compared to other children.

Conclusions about whether siblings of disabled children, including those with developmental disability, are at increased risk for problems also depend on at least two other features of the methods used in research. First, it depends on what you ask about. Most researchers have relied on general measures of psychological and social problems such as standardised mental health or behaviour problems questionnaires, and measures of self-concept/self-esteem. A broader range of outcomes need to be studied if we are to more fully understand the potential social/psychological impact on siblings of having a disabled brother or sister. The results about potential school problems from the Goudie et al. study are a good example. A second issue is that it depends who you ask about sibling problems. The majority of research studies about siblings rely on parent reports. If siblings themselves are asked to report on their own psychological and social difficulties, studies are typically less likely to identify problems for siblings of disabled children (Hastings & Petalas, in press; Rossiter & Sharpe, 2001).

If we do accept that siblings of disabled children are probably at increased risk for psychological and social problems, it is important to ask why this might be or why this happens. To date, very little research has addressed this question. However, existing results are quite consistent in that siblings of children with developmental disability who are the most likely to have increasing levels of problems over time are those whose brothers or sisters have higher levels of behaviour problems (Hastings, 2007; Neece et al., 2010).

2. Relationships between disabled children and their siblings

Research on sibling relationships when one child is disabled is significant because the sibling relationship is a context that has an influence broadly on child development. Positive and supportive sibling relationships are predictive of better developmental outcomes for children generally. Therefore, anything that disrupts sibling relationships may place children at risk for other problems.

Rossiter and Sharpe's (2001) meta-analytic summary of developmental disability sibling research also reviewed research to that date on sibling relationships. Again, the differences between siblings of children with developmental disability and other siblings were small. However, the overall direction of effect was different than for siblings' psychological adjustment: siblings of children with developmental disability were reported (by a mix of parent and self-report) to have *more positive* relationships with their siblings.

In general, as with sibling psychological adjustment, comparison studies have found both improved relationships between siblings and increased difficulties in sibling relationships. For example, Kaminsky and Dewey (2001) compared self-reports about sibling relationships

between 30 siblings of children with ASD, a group of siblings of children with Down syndrome, and a control group. Closeness/intimacy was reported as higher in the group of siblings of children with Down syndrome compared to the other two groups, and lower levels of conflict were reported in the siblings of children with ASD and Down syndrome. In contrast, in a study where sibling self-reports were again compared between a group of siblings of children with ASD and a group of siblings of children with Down syndrome, Pollard et al. (2013) reported less social support in the ASD sibling relationship, more negative interactions, and lower overall quality of relationship.

Given that it is unclear whether having a brother or sister with developmental disability is reliably associated with poorer or better quality sibling relationships, it is important to ask whether there are other variables that are more strongly related to the quality of the sibling relationship. As with siblings' psychological adjustment, there are emerging findings suggesting that when the child with developmental disability has higher levels of behaviour problems, the quality of sibling relationships (whether reported by parents or siblings themselves) is affected negatively (Hastings & Petalas, in press; Petalas et al., 2012a). These findings are also supported by research on sibling relationships in the absence of developmental disability. A meta-analytic summary of 34 studies of non-disabled children concluded that sibling relationships are poorer when one of the children has significant behaviour problems or mental health needs (Buist et al., 2013).

3. The voice of siblings

Researchers studying siblings of children with developmental disabilities have asked the young people themselves to report on their behavioural and emotional adjustment or to rate the quality of their sibling relationships. However, such research addresses questions established in advance and built into the design of the studies. It is also informative to hear the voice of siblings directly, and there is a small research literature where researchers have done just this and interviewed siblings about their experiences of being a brother or sister of a child with developmental disability.

Each study tends to elucidate different themes describing siblings' experiences. However, some common perspectives in recent studies have included: positive experiences of having a brother or sister with a developmental disability including perceptions of their strengths (Mascha & Boucher, 2006; Petalas et al., 2009, 2012b), difficulties associated with the brother or sister's behaviour problems (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Petalas et al., 2009, 2012b), and impact on social activities/peer relationships and the reactions of other people to their brother or sister (Benderix & Sivberg, 2007; Kao et al., 2012; Mascha & Boucher, 2006; Petalas et al., 2009, 2012b).

Gaps in the evidence and some suggestions for future research

Although there has been a reasonable amount of research on siblings of children with developmental disability, the vast majority of studies to date have focused on whether these siblings may face more or fewer problems than other siblings. It is not clear that definitive answers can be achieved even with bigger and better studies. Therefore, we have identified the gaps in current research evidence and some suggestions for future research:

1. Although overall the population of siblings of children with developmental disability may be at only a relatively small increased risk for problems compared to other children, a key question is to be able to **better identify the siblings who are at most risk and may need support**. Research findings so far suggest that we might pay special attention to siblings whose brothers or sisters have high levels of behaviour problems. **Future research attention is also needed on the sub-group of siblings who are young carers**. In recent UK data based on a large sample of young people, 50% of young carers were caring for siblings with a health or disability need (Children's Society, 2013). As a group, young carers were found to perform more poorly in their secondary school (high school) examinations than young people who were not carers. This study did not distinguish young carers of disabled siblings from other young carers, but does indicate the need in high quality research to consider the impact of siblings' caring responsibilities.
2. The range of possible impacts on siblings measured in existing research is quite limited. **More attention is needed on problems that siblings may experience in school, difficulties in peer relationships, and also other domains** suggested from research where siblings have described their own experiences (e.g., embarrassment in public, the impact of other people's responses to the child with developmental disability).
3. Although several research studies have highlighted potential positive aspects of being a sibling of a disabled child, these are poorly described and also poorly understood. More **research is needed to understand the potential impact of positive aspects on sibling outcomes**, either directly or in interaction with more stressful experiences.
4. Little is currently known about the **potential significance of sibling relationships for later outcomes for children with developmental disability or for siblings**. Is a positive relationship with a sibling a context that leads to better outcomes for children with developmental disability themselves? Similarly, does a positive relationship with the child with developmental disability have implications for better developmental outcomes for siblings?

5. Within the UK, as in many other countries, there is significant cultural diversity. However, there are few examples of the study of siblings of children with developmental disability **taking into account different cultural expectations and contexts**. These factors need to be more fully understood.
6. Applied research on siblings has been carried out with the potential to inform supports for siblings, and for families of children with developmental disability more generally. However, there are few examples of research studies evaluating sibling support programmes and none that we are aware of that adopt high quality research evaluation designs on a large scale. **Existing practice and new support interventions for siblings need to be subject to robust evaluation.**
7. Various local and national government policies throughout the world target families of disabled children. However, **the putative impact of current policies and policy changes on siblings within the family is rarely fully considered.**
8. A complete picture especially of sibling relationships when one child has a developmental disability cannot be obtained without **the perspective of the young people with developmental disability themselves**. We are aware of only one research study in which young people with developmental disability were asked about their perspectives on their siblings and their relationships with them (Petalas et al., in press). More research of this kind is clearly needed.
9. A further notable missing aspect of existing research is **the quality of the relationship between parents and the siblings of children with developmental disability**. First, it is not clear whether the parent-(sibling) child relationship may be affected when there is a child with developmental disability in the family. Second, the long term implications of the quality of this relationship may have great practical significance. For example, the involvement of adult siblings with their brother or sister with developmental disability might be related partly to the quality of the parent-(sibling) child relationship during childhood and also into adulthood.
10. The present evidence review focuses on the experiences of siblings who are themselves children and adolescents. However, sibling relationships are life-long. Therefore, **a lifespan perspective on sibling research is needed** not simply through research focused on adult siblings but on sibling experiences over time through childhood and into adulthood.
11. Finally, there are considerable gaps in the research literature on siblings of disabled children and young people. Various **stakeholders** (younger and adult siblings, parents, individuals with developmental disabilities, professionals etc.) **need to be involved in defining the research priorities** for the field.

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