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Article — Published Version

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Journal of Intellectual & Developmental Disability

Provided in Cooperation with:

WZB Berlin Social Science Center

Suggested Citation: Gray, Caitlin et al. (2024) : Down syndrome or Rett syndrome in the family: Parental reflections on sibling experience, Journal of Intellectual & Developmental Disability, ISSN 1469-9532, Taylor & Francis, London, Vol. 49, Iss. 1, pp. 11-24, <https://doi.org/10.3109/13668250.2023.2225353>

This Version is available at:

<https://hdl.handle.net/10419/313070>

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RESEARCH ARTICLE



Down syndrome or Rett syndrome in the family: Parental reflections on sibling experience

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ABSTRACT

Background: Siblings of children with intellectual disability have unique family experiences, varying by type of disability.

Methods: Parents of children with Down syndrome (156) or with Rett syndrome (149) completed questionnaires relating to sibling advantages and disadvantages, experiences of holidays and recreation, and perceived availability of parental time. Qualitative responses were analysed using thematic analysis.

Results: Positive personality traits, an optimistic outlook, enhanced skills, and rich relationships were strong and consistent parental perceptions for siblings in both disability groups. Parents of children with Rett syndrome were more likely to rank themselves lower on time availability, and to report sibling difficulties with social engagement and family holidays.

Conclusions: Parental responses appeared to be influenced by disability type, and reflective of child capabilities. Perceptions of sibling experience should be supplemented by data collected directly from siblings to fully understand their unique perspective, and the ways in which their experiences could be enhanced.

ARTICLE HISTORY

Received 5 July 2022
Accepted 12 June 2023

KEYWORDS

siblings; intellectual disability; Down syndrome; Rett syndrome; parental reflections; family

In developed countries, the prevalence of intellectual disability among children is approximately 2%, with most having a mild level of severity (Bourke et al., 2016). Children with intellectual disability need varying degrees of day-to-day assistance in different areas, including communication, socialisation, learning, and decision-making. Additional medical conditions are often present (American Psychiatric Association, 2013), but the presence and severity of comorbidities is wide-ranging (Doehring et al., 2014; Hamner et al., 2020; Kohane et al., 2012; Leonard et al., 2001; Leonard et al., 1999).

Down syndrome (a condition caused by an additional chromosome or genetic material relating to chromosome 21) (Gilissen et al., 2014; Pangalos et al., 1994; Ropers, 2010), and Rett syndrome (involving mutations in the *MECP2* gene of the X chromosome) (Jeffrey et al., 2010; Leonard et al., 2017) are two genetic conditions associated with intellectual disability. Down

syndrome has a prevalence of approximately 1/1000 live births (Bower et al., 2015; Fitzgerald et al., 2013; Glasson et al., 2016), and is commonly accompanied by minor physical features and various health issues, involving cardiovascular, respiratory, and gastrointestinal systems (Bower et al., 2000; Marder et al., 2015; Thomas et al., 2010; Watts & Vyas, 2013). Children with Down syndrome have many positive attributes and behaviours including for some children for example their expressions of love, affection and joy, their determination, and forgiveness of others (Sheldon et al., 2021). Rett syndrome is a rarer condition, which mainly affects females (Leonard et al., 2017), with a cumulative incidence of 1/8905 females (Fehr et al., 2011). It is differentiated by more severe physical and intellectual impairment, and characterised by loss of communication skills and mobility, presence of hand stereotypies and epilepsy, and difficulties with breathing, sleeping, and feeding (Fabio et al., 2019; Leonard et al., 2017;

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Lidström et al., 1994; Nissenkorn et al., 2010). Mobility equipment is often needed, along with frequent medical appointments and a high level of daily care. Despite the severity of comorbidities, children with Rett syndrome show strengths in their non-verbal communication with their families, for example, use of eye gaze, smile, or hand movements to show their excitement or happiness (Downs & Leonard, 2016; Epstein et al., 2016).

Some parents of children with intellectual disability have been observed to have higher levels of stress, anxiety, and social isolation (Bourke et al., 2008; Dreyfus & Dowse, 2020; Mori et al., 2018; Povee et al., 2012), less personal time (Luijckx et al., 2017), and poorer long-term physical health (Gokcin et al., 2021) and mental wellbeing (Cohrs & Leslie, 2017; Fairthorne et al., 2015; Fatima et al., 2021; Hodge et al., 2013). The impact on siblings in the family can relate to reduced parental attention and resources, disruptions to regular family life, and daily demands, as reported by parents in some families (Luijckx et al., 2016; Moyson & Roeyers, 2012; Povee et al., 2012). Siblings may experience difficulties in various social and community settings when they take on a caring role and additional responsibilities, and may feel anger, guilt, embarrassment and fear (Opperman & Alant, 2003; Shivers & Dykens, 2017; Shivers & McGregor, 2019). Some siblings report significant effects later in life in relation to their mental health and wellbeing (Caliendo et al., 2020; Dervishaliaj & Murati, 2014; Marquis et al., 2019). There are also many advantages for siblings, often relating to positive personality characteristics that develop over time such as compassion, tolerance, and understanding (Mulroy et al., 2008).

Little is known about how influencing factors operating at the family level impact the longer-term benefits and challenges for siblings of children with intellectual disability. In families where care burden is high or less time is available, a reduction in the capacity of family members to engage in recreational or social activities and time away together would occur. Their experiences of family recreation and holiday time has not been well explored. In Australia, several organisations have called for research focusing on the health and wellbeing of siblings (Commissioner for Children and Young People, 2011; Mollenhauer et al., 2013; Royal Australian and New Zealand College of Psychiatrists, 2011; Strohm, 2012). The importance of understanding the experience of siblings of children with intellectual disability is high because, as young children they often need to navigate challenging environments, they are the family members who live the longest along side them, and in many cases they take on caring roles as adults (Caliendo et al., 2020; Dervishaliaj & Murati, 2014; Marquis et al., 2019).

The aim of this study was to investigate, from a parent perspective, the impact of having a child with intellectual disability in the family on sibling experiences. We used parent questionnaire data received from families of children with Down syndrome or Rett syndrome, who were part of a wider program of research on the health of children and adults with either of these two conditions (Anderson et al., 2014; Mori et al., 2018). A previous analysis used data collected at two earlier time points (1997 and 2002) for the two groups, comparing just the advantages and disadvantages for siblings (Mulroy et al., 2008). The current study used later data (collected in 2009) received concurrently from both groups, when many children in these families had become emerging adults. Additional information is presented on parental reflections about sibling recreation experiences and family holidays, and also the perceived availability of parental time, to help understand how the parent perspective varies across families and by disability type. Understanding the parent perspective of the family factors impacting sibling experience may help to unpack ways in which families and siblings can be more supported in their daily lives.

Methods

Ethical approval was provided by the Child and Adolescent Health Service (RGS0000002324, RGS0000002363, RGS0000002390), and The University of Western Australia (ET000787, ET000789, ET000790). Families gave written consent prior to their participation in the research.

Questionnaires that focused on the health of children with intellectual disability were administered to families of children with Down syndrome several times between 1997 and 2011 (Foley et al., 2016) and multiple times to families with Rett syndrome from 2000 to 2019 (Anderson et al., 2014; Fehr et al., 2011; Leonard et al., 1997). Questionnaires were administered using three techniques depending on family preference; postal, online, or by telephone interview. For this study, we used data collected in 2009 when questionnaires for both groups contained the same four sibling questions:

1. Do you think there have been any advantages/benefits to your other children because they have a sibling with Down syndrome/Rett syndrome? If so, please explain.
2. Do you think there have been any disadvantages to your other children because they have a sibling with Down syndrome/Rett syndrome? If so, please explain.

3. Please describe the impact, if any, of having a child with Down syndrome/Rett syndrome on family recreational activities.
4. Please describe the impact, if any, of having a child with Down syndrome/Rett syndrome on family holidays.

Parents were also asked to give a ranking of their perceived availability of their own time for nine domains (sleep, being alone, family, children, partner, friends, socialising, self-appearance, and travel). They reported on a 5-point scale from (1) time was “not at all adequate” to (5) time was “almost always adequate” (Dunst & Leet, 1987). For each domain, a proportion was calculated for the total sum of scores received per disability group out of the total sum of possible scores. The frequency of responses described as “not at all adequate” was also calculated for each domain.

Questionnaires were sent to parents of the children with Down syndrome ($n = 229$) or Rett syndrome ($n = 254$). Families were included in the current analysis if they had at least one other child in the family additional to the child with intellectual disability, and if questionnaires were completed by the family and not another carer. Respondents were a mix of mothers, fathers, and both parents. Children in foster care, adoptive families, or care homes were excluded, as further demographics for these families, including time spent living together, could not be ascertained (Down syndrome, $n = 13$ (6%); Rett syndrome, $n = 28$ (11%)).

Data analysis

Qualitative response data were cleaned and imported into NVivo Software (Feng & Behar-Horenstein, 2019; O’Kane et al., 2021) to conduct a reflective thematic analysis (Braun & Clarke, 2006, 2019). The analysis was not bound by any existing theory but allowed the identification of salient, specific issues that independently guided the development of themes. Hence, initial themes were generated from the content of the responses rather than made to fit pre-existing themes. Responses from the two disability groups were kept separate during coding and themes were derived organically for each disability type. Themes were developed by coding responses and merged to form broader themes when necessary. Trustworthiness was achieved by the following strategies: the development of the theme structure and coding of responses was done by one author (CG), the validation for consistency and accuracy was done by another author (EG), and

additional peer authors were able to confirm validity between the responses and the author’s representation of them. In addition to applied themes, responses to recreation and holiday questions were also coded as having a positive or negative sentiment. Descriptive statistics, reported as median (interquartile range and range), or n (%) where appropriate, were used to summarise the characteristics of the study sample and the responses from the family.

Results

Demographics

Questionnaires were received from 191 families of children/adults with Down syndrome (response fraction 83%), and of these 156/191 (82%) met the inclusion criteria and completed responses to the questions on sibling experience. The age of the child/adult with Down syndrome at the time of questionnaire ranged from 15 to 30 years (median 21 years; 54% male) (Table 1). Among families of children/adults with Rett syndrome, 214 returned questionnaires (response fraction 84%), and of these 149/214 (70%) met the inclusion criteria and completed the sibling questions. The age of the child/adult with Rett syndrome at the time of questionnaire ranged from 3 to 31 years (median 16 years) and all individuals were female. On average, both groups had medium family size (three) and ranged up to eight children.

Perceived parental availability of time

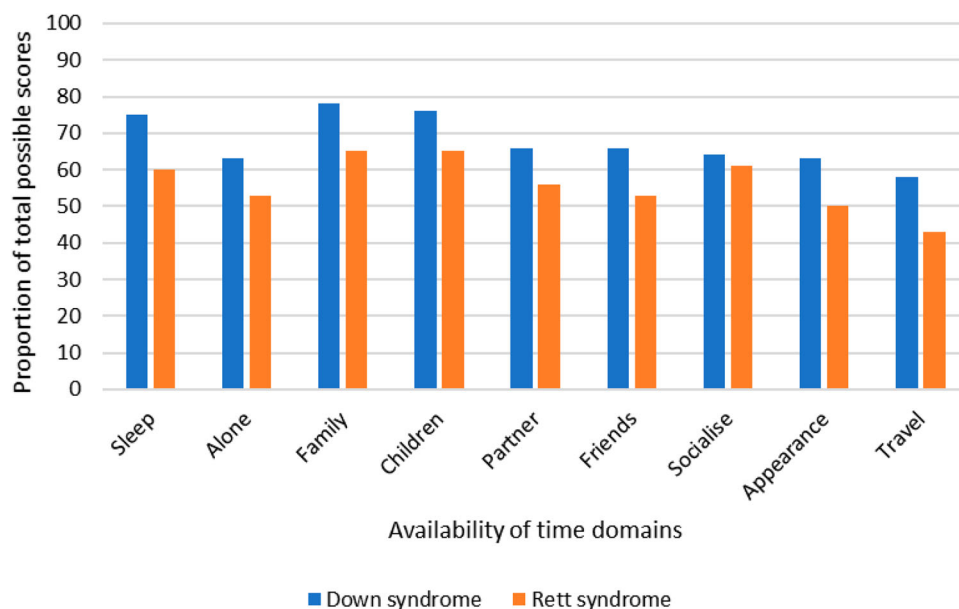
Parents from families with Down syndrome recorded a higher total sum of scores overall (59% vs 53%), and higher scores for each domain than families with Rett syndrome, indicating a stronger overall perception of greater parental time availability (Figure 1). Families with Rett syndrome were more likely to record the lowest rating “not at all adequate” across all domains (Figure 2).

Advantages

Both disability groups gave similar responses about the advantages for siblings of having a child with intellectual disability in the family, in terms of the type of advantage and the frequency of its coding. The top four advantages for both sibling groups included the development of positive “personality traits”, having a better “outlook”, learning life “skills”, and close “relationships” (Figure 3).

Table 1. Demographics of mothers, children with Down syndrome or Rett syndrome, and family characteristics.

Demographics	Down syndrome <i>n</i> (%); median (<i>IQR</i>), range	Rett syndrome <i>n</i> (%); median (<i>IQR</i>), range
MOTHERS	156 (100)	149 (100)
Maternal age at birth of the child with disability (years)	31 (28–35), 19–57	29 (26–33), 17–41
<20	1 (1)	3 (2)
20–24	11 (7)	22 (15)
25–29	45 (29)	52 (35)
30–34	58 (37)	48 (32)
35–39	25 (16)	21 (14)
>39	16 (10)	3 (2)
Age at questionnaire (years)	54 (50–57), 37–80	45 (42–50), 28–64
30–39	1 (1)	2 (1)
40–49	36 (23)	22 (15)
50–59	88 (56)	83 (56)
60–69	26 (17)	37 (25)
>70	5 (3)	4 (3)
CHILD WITH DISABILITY		
Gender		
Male	85 (54)	0 (0)
Female	71 (46)	149 (100)
Age at questionnaire (years)	21 (18–25), 15–30	16 (11–21), 3–31
<5	0 (0)	6 (4)
5–12	0 (0)	44 (29)
13–18	47 (30)	47 (32)
19–25	80 (51)	40 (27)
>25	29 (19)	12 (8)
Position in the family		
Youngest	58 (37)	59 (40)
Middle	51 (33)	33 (22)
Oldest	47 (30)	57 (38)
FAMILY CHARACTERISTICS		
Family size	3 (3–4), 2–8	3 (2–4), 2–8
Small <3 children	32 (20)	56 (38)
Medium 3–5 children	93 (60)	71 (48)
Large >5 children	31 (20)	21 (14)
Birth spacing		
First-born to second child	2 (2–4), 1–20	3 (3–5), 2–15
Last-born to second last child	4 (3–7), 1–14	3 (2–4), 1–16
Sibling ages	25 (19–32), 2–51	18 (12), 1–45
Response levels per question		
Advantages	137 (88)	126 (85)
Disadvantages	112 (72)	132 (89)
Recreation	139 (89)	111 (74)
Holidays	136 (87)	118 (79)

**Figure 1.** Perceived parental availability of time, proportion of total possible scores, per domain, per condition.

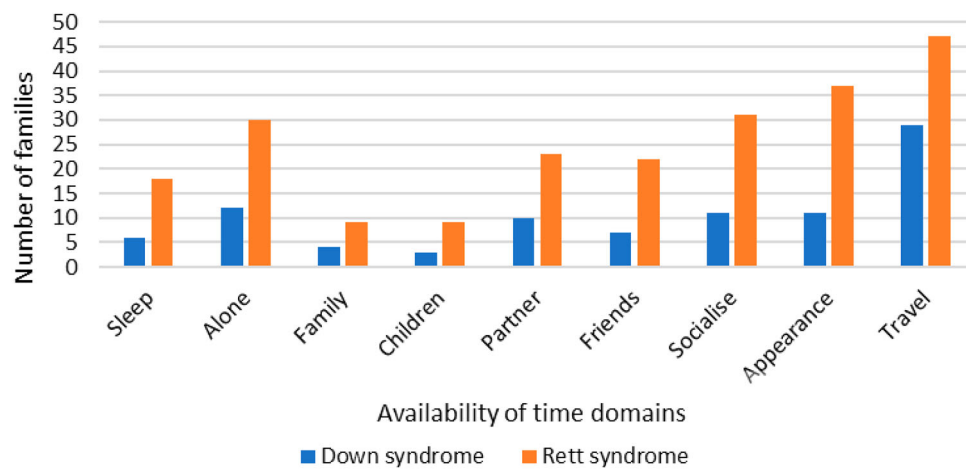


Figure 2. Perceived parental availability of time, frequency of “not at all adequate” responses, per domain, per condition.

Personality traits

For both disability groups, “personality traits” were reported as the most common advantage (92% for families of children with Down syndrome, 85% for families of children with Rett syndrome). Parents indicated traits related to understanding,

“I think having a brother with Down syndrome makes the other boys aware of differences and more understanding of them” and tolerance, “They are more tolerant than their peers towards people with disabilities or problems.” [Down syndrome]

A caring nature

“Our daughter has a very caring side to her friends who are far less fortunate” and being patient, “They have learnt to wait for what they want, or accept compromise, to make allowances for someone whose needs are more urgent, gained knowledge and experience of caring for a disabled family member.” [Rett Syndrome]

Outlook

The second most commonly recorded theme for advantages for both disability groups was “outlook” referring to a positive outlook on life (35% Down syndrome, 52% Rett syndrome). Responses centred around siblings having an increased awareness of diversity among people, an acceptance of others, feeling comfortable around difference and different abilities, and a sibling’s capacity to realise what is important in their lives and appreciating that of others.

“Greater understanding of differences and have a strong sense of social justice for all. Great fondness for other people with Down syndrome. Strong advocates.” [Down syndrome]

“It gives them an understanding of other families with children with disabilities. They are more accepting of people who are different.” [Rett syndrome]

Skills

Under the theme “skills” (24% Down syndrome, 30% Rett syndrome), most responses from both groups were about the indirect learning they experience at home, and how that equips them with the skills necessary to cope later in life.

“Developed their capacity to love and care for others especially those who are vulnerable” and “More sensitive to others’ emotions, inclusivity, ways of communicating, allowing more time for others.” [Down syndrome]

Responses also referred to direct learning where siblings learnt skills at earlier ages through participation in therapies or aids intended for the child with disability.

“He is popular because of his social skills which have been hammered into him from a young age, by participating in all the therapies his sister has had since he was a baby” and “We believe the additional communication aids have benefited our second child due to her inclusion in reading and singing sessions as a small child.” [Rett syndrome]

Relationships

Responses for “relationships” (21% Down syndrome, 25% Rett syndrome), indicated a sense of richness in the relationships within the family and between the children.

“It has made my family love one another and bring us together in times of hardship. He is a blessing to our family. All my children love him more than anything in the world.” [Down syndrome]

Comments also referred to future relationships;

“(they have) developed their capacity to love and care for others especially those who are vulnerable” [Down syndrome]

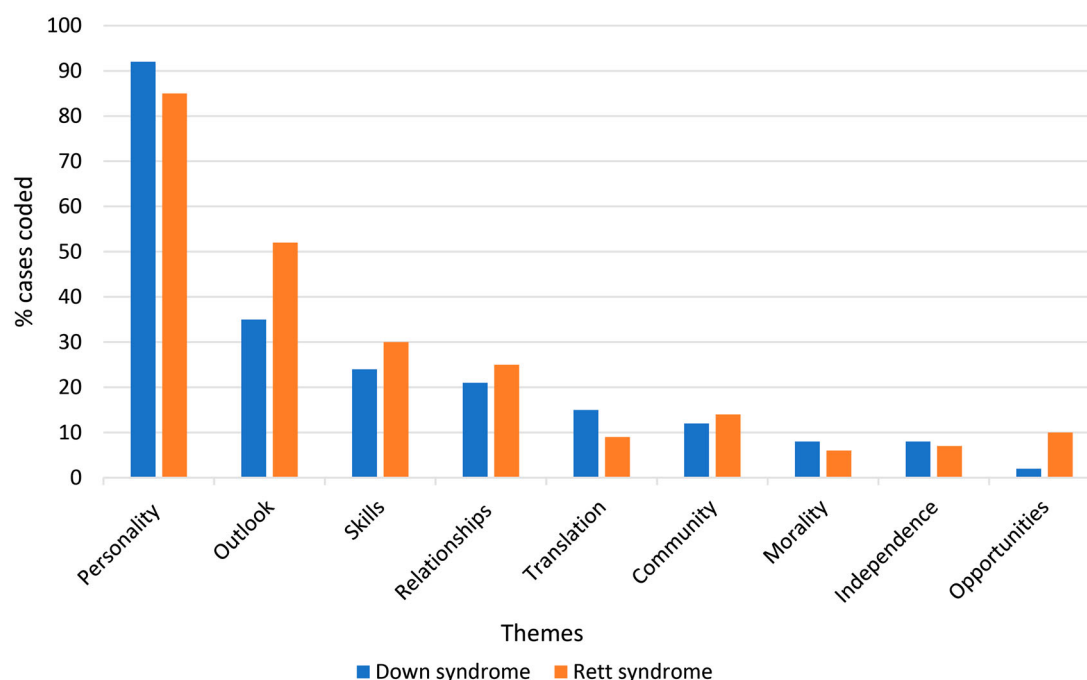


Figure 3. Parent perceived advantages for siblings of children with Down syndrome or Rett syndrome.

syndrome], and unconditional love, “They understand unconditional love because their sister can’t verbally express how she feels about them but they see it in her facial expressions and reactions to them when she sees them or hears their voices on the phone.” [Rett syndrome]

Disadvantages

The most common disadvantages reported by the two groups of parents were “time”, “missed opportunities”, “impact on relationships”, and “less attention for siblings” (Figure 4). For “missed opportunities”, families

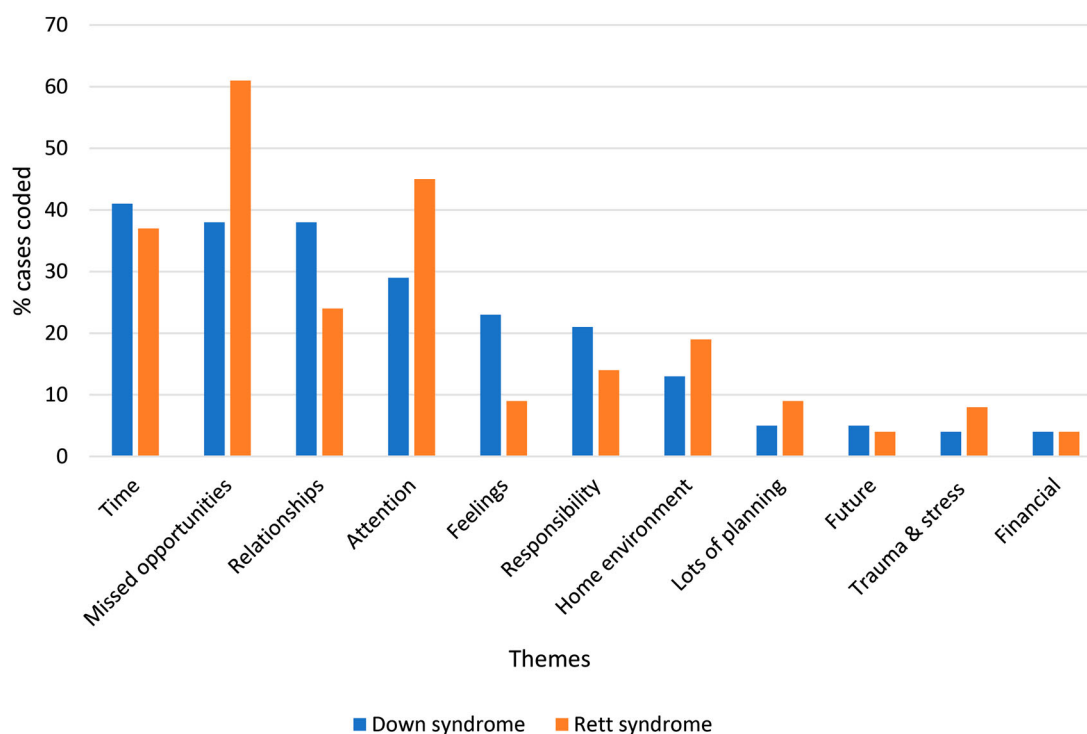


Figure 4. Parent perceived disadvantages for siblings of children with Down syndrome or Rett syndrome.

with Rett syndrome had more responses (61%) than families with Down syndrome (38%); and for “less attention for siblings” families with Rett syndrome also had more responses (29% Down syndrome, 45% Rett syndrome).

Time

Around 40% of responses from both groups stated that siblings were disadvantaged in terms of their own, and their parents’ “time”. Parents spoke of siblings forgoing personal time to help care for or supervise their sibling, and parents not having enough time to devote to them or their interests, because of time devoted to the child with disability. Limitations on time for sibling activities and socialising were specifically mentioned by both groups.

“They sometimes have to make allowances for their brother such as giving up their time to help him with tasks; staying home with him. If I have to be away and generally, be on a look out for him when in or out of home.” [Down syndrome]

Missed opportunities

Responses associated with “missed opportunities” related to social and home settings, and were more common among families with Rett syndrome (38% Down syndrome, 61% Rett syndrome). Comments reflected an inability for siblings to experience some of the regular activities often undertaken in “typical” families during childhood.

“They missed out on family outings and holidays because it was just easier to stay at home. I feel extremely bad about this.” [Down syndrome]

Comments made by families sometimes suggested a sense of injustice.

“They have missed out on individual time that children deserve when they are growing up, i.e., they went from being 9 years old when their sister was diagnosed to being 20 years old and taking on extra responsibilities.” [Rett syndrome]

Impact on relationships

Parents spoke about the impact on friendships for siblings, particularly not being able to have friends over to the family home because of challenging behaviours, and reduced interaction with friends.

“Lack of interaction with his friends. Had to look after his sister when I was at work” and “They are embarrassed by her behaviour at times, and this has caused them not to bring their friends home.” [Down syndrome]

Parents also spoke about the relationship between siblings, alluding to uneven sibling relationships.

“Not growing up with a sister that could communicate on his level. Especially when they became teenagers. Not having a sister to go around with, within their friend groups” and “The sibling who is younger than the child with Down syndrome has wished for a more equal relationship as he has been the only other sibling at home in recent years.” [Down syndrome]

Responses describing the impact on sibling relationships with peers, siblings, and friends were more common from parents in families with Down syndrome (38% Down syndrome, 24% Rett syndrome). Comments specifically related to being teased and bullied, usually within a school setting where children attended the same school, were almost exclusively found among families with Down syndrome.

“Having our child with Down syndrome at the same schools in primary years made a few challenges with unkind children for his siblings” and “Having to defend his sister from taunts to him by peers, occasionally becoming involved in physical fights.” [Down syndrome]

Less attention for siblings

Responses relating to “less attention for siblings” included those pertaining to reduced parental involvement and coming second place, and were reported more commonly among families with Rett syndrome (29% Down syndrome, 45% Rett syndrome). Parents indicated that siblings sometimes received less attention, both within and outside the family home.

“Most of our way of life is centred around her so life is not as spontaneous as he would like. Sometimes it’s hard to monitor school issues like homework as my attention can be drawn away.” [Rett syndrome]

Parents also reported that after caring for the child with Rett syndrome, they were too tired or felt physically and emotionally exhausted to properly attend to their other children.

“I am more focussed on the needs of my child with Rett syndrome than the needs of the other children. I have less time to help them with work and less time to do things with them. I’m often so physically exhausted at the end of the day, even in pain, that I can get very irritable” and “More stressed parents, often at hospitals or on phone regarding our daughter, or on computer writing letters.” [Rett syndrome]

Feelings

While this theme did not have a large amount of responses, differences were noted between the two disability groups (23% Down syndrome, 9% Rett syndrome). For families with Down syndrome, embarrassment emerged from responses, initially seen

when families spoke about relationships and public settings

“Embarrassed in social situations with her behaviour.”
[Down syndrome]

For families with Rett syndrome, parents spoke about siblings experiencing stress relating to care needs.

“The home environment has often been more stressed, with unexpected crises with sister needing immediate attention. We drop everything until crisis is over.”
[Rett Syndrome]

Recreation

The most common responses to recreation for both groups were predominantly negative (60% Down syndrome, 79% Rett syndrome), with responses more common in families with Rett syndrome, and related to “family isolation,” followed by “limitations to activities,” “access to recreation”, and “capabilities of the child with disability” (Figure 5). Many parents in families with Down syndrome reported there was “no impact” on sibling recreation opportunities in their families (36% Down syndrome, 9% Rett syndrome).

Family isolation

Feelings of being isolated from the community were more common among families with Rett syndrome (28% Down syndrome, 50% Rett syndrome). Some

parents reported a sense of futility, that they would not even try to participate in community events due to difficulties associated with their child participating.

“Our life revolves around her and ‘normal’ family activities are few and far between” and “There are many things that we cannot do because of her health, or because it is not easy to manage outings with all of the equipment required for her.” [Rett syndrome]

Other comments reflected on reductions in participation over time.

“Recreational activities outside the home became very limited. These activities did not “grow up” and change as the family did. Participation at the many sporting or educational events of our other children was often difficult, e.g., socialising with other parents could not happen smoothly.” [Down syndrome]

A sense of “family divide” was more often spoken about in families with Rett syndrome, the idea of not being able to have the whole family join in, or only one parent.

“We tend to do things separately, the family has become very fragmented. If we do try to have family activities, they have to include a carer which then loses that intimacy of just family.” [Rett syndrome]

Limitations to activities

Families described limitations for siblings in their recreation, including location, transport, finances, time, and behaviours, more commonly for families

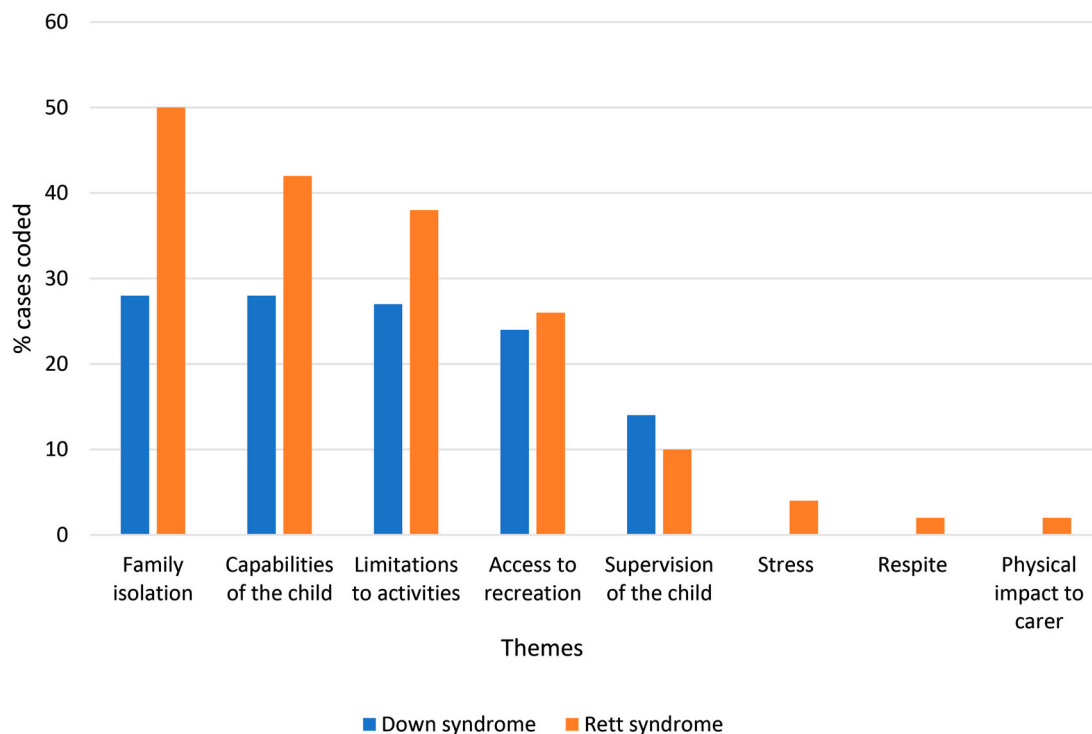


Figure 5. Parent perceived impact of having a child with Down syndrome or Rett syndrome on family recreation activities.

with Rett syndrome (27% Down syndrome, 38% Rett syndrome).

“We have often had to leave a venue without notice and quickly because of her disturbance. We are very limited in our activities and we do not risk taking her anywhere she may be of great disturbance such as a movie theatre.” [Rett syndrome]

“It was sometimes difficult to take my other children to participate in recreational activities if my daughter was not cooperative.” [Down syndrome]

Access to recreation

Parents spoke about “planning” and “inclusivity” involved to access recreational activities (24% Down syndrome, 38% Rett syndrome),

“Lots of effort and planning did minimise the negatives” and “We often plan family recreations activities around my son’s interests so that we can all be involved.” [Down syndrome]

Families with Rett syndrome spoke about environmental barriers, such as wheelchair accessibility, lack of suitable parking, and limited availability of equipment, and that sometimes this meant that siblings might miss out on some activities.

“Restricts us from doing a great deal, too difficult to transport wheelchair and also to gain access to various places” and “Always need to ensure that access is easy. Playing on the sand is a little challenging as she is getting heavy to carry but her wheelchair will not go over the sand.” [Rett syndrome]

Capabilities of the child with disability

Both groups mentioned the capabilities of the child with disability impacting on family recreational activities (28% Down syndrome, 42% Rett syndrome). The families with Down syndrome spoke more about developmental capabilities, with siblings sometimes missing out on outdoor or indoor activities such as certain board games or movies, because the content was unsuitable. Families with Rett syndrome spoke more about physical capabilities, mobility, and tiring of the child.

Holidays

Many families of children with Down syndrome (35%), and fewer for families of children with Rett syndrome (11%) reported there was “no impact” of having a child with disability on family holidays;

“I don’t feel there is much of an impact because we are happy to adapt to his needs.”

“No impact at all. She was just one of the kids.”

“None really, we all enjoy our holidays as a family.”

“There has been no impact as she went everywhere with us.” [Down syndrome]

Of families giving a response other than “no impact”, the majority were negative (63% Down syndrome, 75% Rett syndrome). Comments related to:

Restrictions in holiday choices (36% Down syndrome, 33% Rett syndrome) (Figure 6);

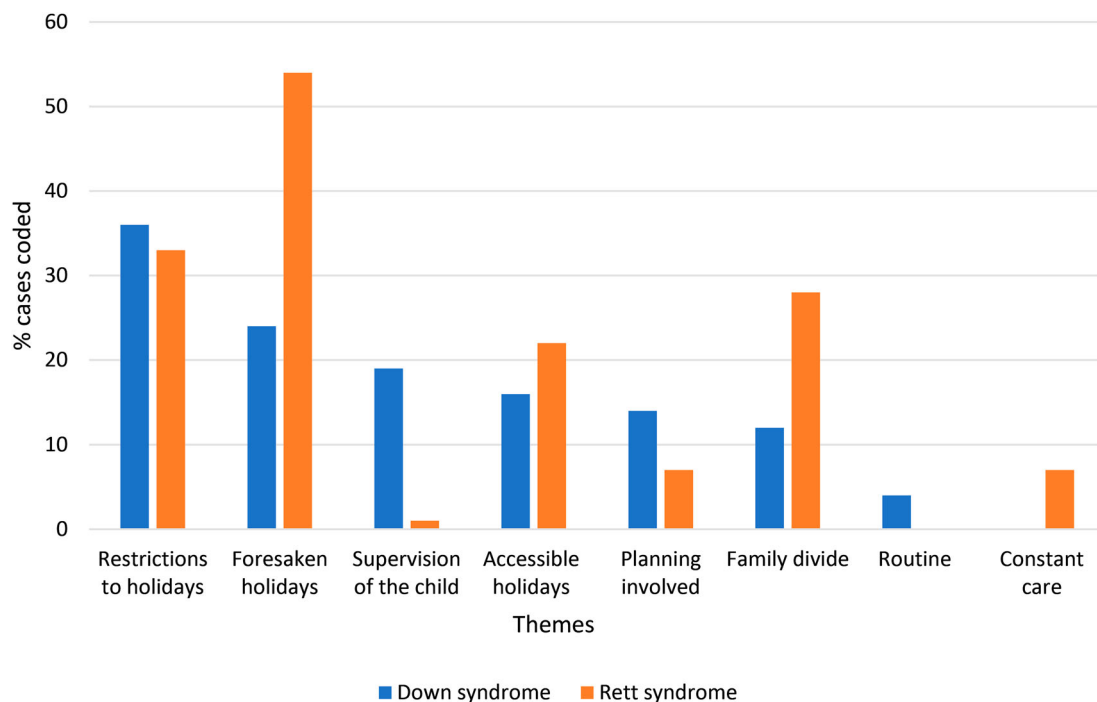


Figure 6. Parent perceived impact of having a child with Down syndrome or Rett syndrome on family holidays.

“Her seizures cause us to be alert. Regular stops during car trips to walk her means we take longer. Working between seizures, toileting and PEG [percutaneous endoscopic gastronomy] feeds mean no one-day long trips. No plane trips.” [Rett syndrome]

Forsaken holidays (24% Down syndrome, 54% Rett syndrome);

“Due to the amount of physical work involved, I don’t feel it is a holiday when you are doing the exact thing, just in a different location.” [Rett syndrome]

Supervision (19% Down syndrome, 1% Rett syndrome);

“You can’t take him on a family holiday, it’s a complete nightmare, you can’t sleep because he just won’t go to sleep in a foreign environment, and you can’t lock the doors in such a way he can’t open them on holiday.”

“We found holidays very stressful on the whole, due to my daughter’s wandering.”

“Overseas, have to organise respite or take him with us, have to watch him like a hawk as no sense of danger and doesn’t worry about the traffic.” [Down syndrome]

Family divide (12% Down syndrome, 28% Rett syndrome);

“We don’t go on holidays anymore as a family. Rett daughter stays behind with a carer which is very upsetting but don’t see any alternative, as is only chance to have a break” and “Doesn’t happen for us. I took sibling overseas for a holiday and husband and daughter with Rett syndrome stayed home.” [Rett syndrome]

Discussion

This study found that siblings of children with Down syndrome or Rett syndrome develop unique personal benefits from living with disability in their family, as perceived by parents. Perceptions of siblings developing positive personality characteristics were commonly and consistently reported and these advantages infer life-long benefits. However, parents report siblings can be disadvantaged with respect to aspects of family life, including parental time, missed opportunities, social interaction, recreational activities, and family holidays. Responses may have been influenced by framing of questions through a more negative lens, but the content and themes provide insight into the times when experiences can become the most challenging for families. On average, parents of children with Down syndrome perceived more time was available to them than parents of children with Rett syndrome across all measured domains. The differences in parental responses appear to be influenced by disability type, and reflective of child capabilities or family characteristics.

This study has a number of strengths. Firstly, we involved large numbers of families and had high response fractions for both disability groups, which is particularly valuable for families of children with Rett syndrome because of the rarity of the diagnosis. Secondly, the same questions were asked of parents at the same time point, allowing responses to be considered in the same spatial context. Thirdly, reflections on family recreation and holidays, and perceived availability of time allowed for greater breadth of discussion of specific family experiences.

Previous literature using parent report has shown that siblings appear to have an increased understanding, and greater awareness, of disability, are reportedly more comfortable around other people with disabilities, and have greater acceptance and enhanced understanding of disability. (Dyke et al., 2009; Mulroy et al., 2008; Nielsen et al., 2012). Findings of reduced parental attention and resources, restrictions to socialisation, disruption to regular family life, new demands, and adaption to a different lifestyle have also been reported (Luijckx et al., 2016; Moyson & Roeyers, 2012; Opperman & Alant, 2003; Povee et al., 2012; Shivers & Dykens, 2017; Shivers & McGregor, 2019). A subset of families in this study was approached 7–12 years earlier to describe sibling advantages and disadvantages (families with Down syndrome in 1997, and families with Rett syndrome in 2002) (Mulroy et al., 2008), when the children with disability were on average in mid-childhood (Down syndrome 11 years, Rett syndrome 14 years). The current research analysed responses to the same two questions when the children with disability were on average adolescents or young adults, and family sizes had grown on average by one child. Similar to the initial analysis (Mulroy et al., 2008), families in this study reported sibling benefits of close family relationships and positive personality characteristics continuing into adulthood (Mulroy et al., 2008; Nielsen et al., 2012). This suggests there are strong perceptions of sibling advantage that persist over time. The findings also confirmed that some challenges for siblings continued to exist, with unique responses received from the two groups relating to different types of disability.

This study offered specific insight into the perceived impact of disability in the family on sibling experience of recreation and holidays. Responses were mixed and more variable among families with Down syndrome. Parents from families with Down syndrome gave more positive responses with regard to inclusion in family activities outside the home, also noting that issues surrounding limitations, planning, and supervision had an impact on experiences within these settings. Some parents of children with Rett syndrome who

reported non-participation or family divide, stated that activities were sometimes impeded by the need to prepare, and physical difficulties with equipment preventing them from engaging fully (Nyman et al., 2018; Woodgate et al., 2016). Siblings of children with intellectual disability therefore have varied recreational activities and holiday experiences and further exploration of how to successfully engage in these settings is warranted.

Apart from the presence of specific disabilities, the differences between the two disability groups may have been impacted by family structure. On average, children with Down syndrome had more siblings than children with Rett syndrome and were older (4 vs 3 siblings; 80% vs 62% medium to large families; 25 vs 18 years). Having a greater number of siblings in the family could have more benefits, with more people offering support in the family unit, more opportunities for socialisation, and distribution of responsibilities (Lee et al., 2019; Lemoine & Schneider, 2022). This may have resulted in the finding of more perceived time among parents of children with Down syndrome if they were more likely experience shared workloads, or if there were older children, or fewer children, living at home. Parents of children with Down syndrome were on average older than parents of children with Rett syndrome (54 years vs 46 years), indicating more parenting years, or a greater maturity in their parenting years, to reflect on sibling impacts. Longer parenthood time could relate to the effects of parental resiliency (Beighton & Wills, 2017). On average, children with Down syndrome were also older than children with Rett syndrome (22 years vs 16 years) at the time of questionnaire. This may reflect a reduction in impact for siblings as the child with disability becomes older (Esbensen et al., 2008; Foley et al., 2016), or a bias in recall that parents are less likely to report negative early memories, or that parents may reflect on more recent memories.

This study used pre-existing data and therefore it was not possible to modify the method of data collection, as such the assumptions made on sibling experience and wellbeing were based on parent report in the context of the questions asked. Engaging siblings of children with intellectual disability directly for their own opinions regarding their family and social life would shed valuable insight into their own experiences. The use of pre-existing data also may not align closely with continuing changes that occur in policy and funding. However, given the large size of the study especially for Rett syndrome and the current gaps in the literature, particularly with regards to recreation and holidays, these results provide unique data on parent perspective

to build future research in this area with respect to current practices. Another limitation was that the responses were not analysed with respect to the spectrum of severity levels of the children that occur within each disability group, by the level of support that families were able to access, or by ethnicity. This would allow greater understanding of sibling experience in relation to varying child capabilities in both groups, and the extent to which family-based support, including culturally appropriate support, may contribute to positive experiences. A third limitation was the inability to pinpoint particular impacts at certain ages, as it was uncertain which time periods parents were reflecting, particularly as many siblings had reached adulthood. A longitudinal analysis comparing responses from the same families over time would allow a more comprehensive life-course view of sibling impact as they age.

Findings from this study suggest that siblings could benefit from greater acknowledgement and support as they age. Further work to understand the barriers to sibling involvement in sport and other recreational opportunities (via schools or other community services) is needed, as is a more detailed analysis of how families with children with severe disabilities could manage holiday time together. Using a strengths-based approach, programs aimed at building sibling capacity more broadly, or targeting resilience and coping skills for all family members would provide long-term skillsets that could be utilised across environments and over time. Wider disability education and acceptance could assist in creating a more holistic model of disability awareness and care in the general community that would have direct benefits for siblings.

In Western Australia, since these sibling data were collected, changes to disability funding have emerged through the National Disability Insurance Scheme (NDIS) (Boaden et al., 2021; Gavidia-Payne, 2020; May et al., 2018; Ranasinghe et al., 2017; Russo et al., 2021) with an individualised model of funding, where families have greater flexibility on how their funding can be used. It would be valuable to examine ways in which utilisation of funding models impacts sibling experiences. An examination of existing policy, barriers, and enablers for sibling supports could be conducted, and when combined with family-level data, could result in a comprehensive description of needs and gaps, practical solutions, and recommendations across sectors.

Conclusions

Positive and negative experiences for siblings of children with intellectual disability in the family are

reported by parents to exist across family life, including family recreation and holidays. These experiences persist over time and across different types of disability in the family. A spectrum of impact exists, where siblings may be largely unimpacted, or miss out entirely on activities resulting in more social isolation and family division. More information is needed from siblings' own voices, and in what ways siblings could be better supported.

Acknowledgements

We thank families for their valuable contributions and time completing our questionnaires.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This research was supported by an Australian National Health and Medical Research Council (NHMRC) Grant [1184770], and a Senior Research Fellowship [1117105]; and a University of Western Australia Scholarship (RTP/UPA).

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