



## Report

# Aggression toward siblings from a brother or sister with disability

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## Acknowledgements

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## Executive Summary

Research and anecdotal evidence supports the view that illness and disability affects the lives of all family members. Over recent times there has been more emphasis on the concerns of siblings and their need for support. This report outlines the responses to a small survey Siblings Australia developed regarding the physical aggression experienced by some siblings from their brother or sister with disability. It was not a statistical research piece but more an anecdotal one in order to gain more information about the issues. The findings support the idea of more support for whole families when a child has disability.

## Introduction

Since 1999, Siblings Australia has been the only organisation in Australia to focus specifically on siblings of children with disability or chronic illness. During that time it has developed a range of resources and services, run workshops around Australia and overseas for parents and service providers, carried out research and lobbied hard to have siblings recognised as a group in need of support.

Most of the research on growing up with a brother or sister with disability has focussed on the social and emotional impacts. Certainly there is a mix of responses from siblings. Whilst some siblings take mainly positive things from their experiences, certainly many siblings face challenges and, without support, are at risk of developing longer term mental and physical health problems. For example, the 2008 Australian Institute for Family Studies report<sup>1</sup> found that siblings of children with disability had higher rates of depression regardless of any caring role they may or may not play. The Royal Australian & New Zealand College of Psychiatrists, in late 2011, released a [Position Statement](#) and Issues paper which also highlighted the risks for siblings.

In recent times the Director of Siblings Australia has been increasingly concerned by the stories of harm told to her at parent and provider workshops, not only about emotional harm but also physical harm done to siblings by a child with disability. Stories have been told at these workshops about siblings ending up in emergency with broken bones, needing stitches or other medical treatment.

It is a very difficult subject to discuss as there are such conflicts of loyalty experienced by families. In addition, no-one wants to add to the stigma experienced by children with disability and this was certainly not the intention of this project. The main aim of this work is to shine a light on the issue in order to raise awareness. It is hoped that greater awareness will lead to more resources and services to strengthen all family members.

The sample for this survey was by no means exhaustive. Siblings Australia posted information about the project to its Facebook page and to its database of over 1200 people. There were separate surveys set up for parents, siblings and service providers.

A couple of responses indicated some disagreement with the principle involved in carrying out this research, suggesting that we should not be looking at this issue. One provider said they felt the emotional effects were more important than the physical ones and that they were disappointed the survey did not focus more on those. Some commented that many families do not experience aggression and that the survey did not really cater for those.

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<sup>1</sup> Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N., Kingston, M. (2008). The nature and impact of caring for family members with a disability in Australia. *Australian Institute of Family Studies, 2008. Research Report, no. 16*

However, the purpose of the survey was not to address those families who do not experience aggression. We know already that the vast majority of families do NOT experience aggressive behaviour from a child or young person with disability. We have also done much work over the years on the emotional effects on siblings. What we wanted to know was whether aggression is an issue for some families.

With limited resources available to us we could not quantify the problem – a much bigger research project would be needed to be able to do this. We wanted to get a sense of the problem.

From parents, we received over 100 completed surveys which indicated aggression as an issue. There were approximately 140 total responses but the extra 40 were surveys that were started with basic information but none of the questions re aggression were answered. The results of this survey cannot be used to quantify the problem but, for a small sample, the results indicate a problem worth further investigation.

We also received completed surveys from 40 siblings and 46 service providers – all of which indicated a problem of varying severity. Again, after giving some basic demographic information, some people did not complete the survey.

## Results

### 1. Parent survey

Some of the responses from parents involved more than one child with disability and more than one sibling. This report has tried to condense this information as best as possible. However, total numbers are higher than listed due to this overlap. It also means that the totals below are not always consistent. All of the information below relates to survey responses that indicated a level of aggression by a child with disability. Other responses were not included.

Questions 1-5 Demographic information

State where live	SA 55; NSW 20; WA 20; Victoria 16; Queensland 6; NT 2; ACT 1
Gender of child with disability	Male 80; female 30
Age of child with disability	7yrs or under, 30+ 8-18yrs, 58 over 18yrs, 16
Gender of sibling	Male 48; female 64
Age of sibling	7 yrs or under 35 8-18yrs 55 over 18 yrs 18

NB Of the 35 siblings under 7 years of under, there were 24 who were under 4 years.

### 6. Type of disability

There was a range of disability through the responses. The responses make it difficult to quantify the level of aggression based on the type of disability. Most of the examples were of children on the autism spectrum, including Aspergers, but there were other disabilities included cerebral palsy, Down syndrome, Intellectual Disability, various genetic syndromes and mental illness. There were several with a dual diagnosis.

### 7. Physical aggression

There was a broad range of physical aggression, ranging from over-zealous play that might lead to physical harm being done to more serious injury.

Certainly many respondents indicated that they and their children who are siblings live in constant fear of physical aggression by the child with disability. Some parents said that siblings aggravate the situation with their brother or sister at times, by 'pushing their buttons'. Some examples of what parents said include:

*Very physically aggressive, stabbed him with scissors just yesterday*

*Older son frequently lashes out at his brother - hitting, kicking and increasingly putting hands tightly around his neck*

*It is still happening. He will punch, kick, bite (till there is blood and also tooth marks), slam her into things e.g. walls, doors and strangle his sister. It has been happening for the past 3-4 yrs. He has also put her through a window but luckily enough only the window broke.*

*Severe biting, choking, kicking, pinching, punching, spitting on, cruel*

*When he is upset he used to hit the siblings hard by punching them. For awhile, the kids used to run and hide from him until I sorted it out.*

*Hitting, biting (sometimes severe), pushing, punching, shouting, scratching, kicking, throwing objects at sib, spitting, choking, pulling hair, pinching, sexual aggression, bruising*

*Punching repeatedly and constantly telling her she is fat and ugly*

*Controlling her with force*

#### 8. Emotional harm

There were a range of behaviours that were identified as causing emotional harm to a sibling, for example: yelling, screaming, name calling, destroying 'treasures', repeatedly telling sibling she is 'stupid', rude gestures, laughs when sibling hurt, hiding things that are important to sib, putting down, picking on sib, saying nasty and hurtful things, destroying belongings of sib e.g. toys or clothes, swearing, manipulation, suicidal and homicidal threats, constant belittling of sib. Prevents sibling from doing what he likes, e.g. aggression expressed in response to singing. Tells sibling to shut up whenever she speaks. Parents said that siblings often 'shut down'; some identified depression and anxiety as an outcome. Parents also said that siblings live in fear, e.g. a 3 year old cowers every time his brother comes close; others constantly worry that they might get hit. Some are constantly screamed at, often right in their face. Others are forced to do things they don't want to do.

Parents identified a number of other issues e.g. that siblings miss out on so much as the family cannot go out; sibs experience rejection and isolation, some no longer have contact; siblings feel left out and unloved; they are distressed by embarrassing behaviour in public; sibs do not understand why the brother or sister with disability is so aggressive as the sib has done nothing to deserve it.

#### 9. Medical attention

Most parents had not sought medical attention for a sib. Many said that their children had been hurt but it had never resulted in a medical emergency. Some said that there were many occasions when there was bruising or a need to check for broken bones over the years. Some said they attended to wounds at home. Several said their children were having psychiatric and psychological treatment due to the stress, anxiety or depression. One sibling needed emergency dental treatment the second time she was subjected to aggression – the first time this happened it was only her baby teeth so no treatment was required.

Other parents talked of needing medical attention themselves because they came between the children. Many said they had to be extremely vigilant watching out and having to make changes to the home environment to protect their children.

Others talked about sibs being willingly involved in rough play but then not being able to extract themselves when it gets too rough. Sometimes this had resulted in broken bones.

A couple of parents mentioned inappropriate sexual behaviours toward a sibling.

On the whole, responses indicated that medical attention was not sought. However, given the size of this survey it is difficult to know how many siblings need medical attention. Also, several parents indicated that they and other parents do not seek medical attention for fear it might be reported and then they are afraid of what might happen from there. For example, one parent reported going to the GP but the *'GP wanted to report the assault to the police therefore we do not seek medical attention anymore'*.

#### 10. When is aggression happening

Again, there was a variety of responses to when the aggression occurs. In some cases, the aggression escalates as a child gets older, especially approaching adolescence; in other cases it eases off as the child ages. But parents talked of this being a constant in their child's life, some saying that aggression and abuse have ALWAYS been an issue. One parent said that whilst the frequency had moderated a little, when he does hurt his sister it is *'more powerful, harmful and hurtful as he is so strong'*.

One family had relinquished the care of the child to the State several years earlier in order to protect the sibling. Some of the aggression reported by parents was directed toward very young children – babies and toddlers.

### 11. Sibling survey

Again all figures may not match up as some questions were not completed

Location of respondent	ACT 1, NSW 11, NT 2, Qu, 4, SA 14, Vic 5, WA 7	
Gender of sibling	Males 8	Females 32
Age of sibling	7 & younger	5
	15-17 years	6
	18-29	8
	30 and older	7
Gender of person with disability	Brothers 27	Sisters 13
Age of person with disability	Under 8	2
	8-10	12
	11-13	7
	14-16	5
	17-20,	4
	21-29	5
	30 & older	6
Type of disability	Majority on the autism spectrum; some have dual diagnosis with something else e.g. epilepsy, ODD, ID. A few have Intellectual disability, a few have physical disability and there were a mix of other genetic syndromes and one has a mental illness.	

#### 1. Physical aggression

Most common forms of aggression reported by siblings were kicking, hitting, punching, pinching, pushing, biting, scratching, and pulling of hair. A few mentioned strangling. Also, verbal abuse, eg, yelling and screaming, was prevalent. One young person said it was now directed at her mum as she had moved out to go to uni. A few examples include:

*Spitting in my face, kicking, hitting, throwing things at me, pulling my hair*

*He hits and kicks me sometimes and squashes me too hard so I can't breathe sometimes and it scares me*

*I've been punched by my brother, pushed around, snatched from, I've got bruises from him, sometimes cuts, and even bite marks*

*She can hit, push, aggressively hold onto you, pinch, and scratch when in particularly low phase. It usually begins as an argument that my sister creates (the argument always has no real basis) and escalates over several hours (which is exhausting), until she is violent. She is often crying during this time and accusing us of not loving her which is upsetting.*

*Yes my older brother gets angry at me and it scares me a lot.*

*Yells swears and throws things - this is frustrating and makes me angry*

*I get bitten, choked, scratched, pinched and punched a lot*

*I get hit, punched, smacked and bitten. I have things thrown at me.*

*When she and I were younger, she was violent. She would chase me, hit, kick, bite and pull my hair. Nowadays, her medication has stabilised her moods but she can still be unpredictable and aggressive*

## 2. Emotional Stress.

Verbal abuse was the main form of emotional aggression, such as yelling, calling names, personal insults, swearing. Some examples follow:

*He calls me names and says he hates me and says he wishes he didn't have a brother sometimes. He calls me a baby and never thinks what I do is any good.*

*It can be scary*

*I feel like giving up sometimes, he doesn't stop, and whatever I do, it doesn't seem to get through to him that he hurts me*

*She always picks on me and makes me feel bad about myself. Calls me names and tells me I'm fat. She puts me down a lot.*

*She is often manipulative which is emotionally straining. And she uses guilt to affect my emotions. She is verbally abusive to my father and mother, with attempts from me to get her to stop usually met with similar verbal abuse. Watching my elderly parents suffer this daily is emotionally draining.*

*On occasion he will scream he hates us and wants us dead.*

*My brother yells and screams at me most of the time.*

*Her moods and behaviours are still very emotionally draining. I no longer live at home but as she is so sensitive and unpredictable and unable to cope with change, she still hurts me emotionally.*

## 3. When aggression happening

Some siblings talked of aggression happening now or in the past. For some siblings, experiences of aggression are very regular, i.e., ongoing and every day. Some said it happened all through their childhood. For some it had increased as the child aged, for others it had reduced in intensity. Some said it had reduced as they now avoided contact and there was little interaction. Some had moved right away from the family. One sibling was advised at 18 to move out of home by her brother's psychiatrist because of the behaviour. Some talked of the violence happening whenever the child had a tantrum, sometimes not specifically targeted at the sibling but toward anyone who was nearby.

Some examples include:

*It happens all the time, but I know when to leave him alone now as I am getting older and know him better*

*The aggression occurred about 15 years ago. I no longer see my brother due to the violence against my sons.*

*It has happened all of his life once he could walk.*

*Occurs on and off depending on how frustrated she is with the limitations on her life.*

*It is happening now, it only happens when he has a tantrum towards me, it can last from 10 minutes to over an hour.*

*She has been doing this since I was about 11 and I'm almost 18 now. Sometimes it's really bad and other times she eases off a bit. It's ongoing.*

*My sister seems to have low/high periods that go for months at a time. Usually once a year a low period will peak in her being violent- usually aimed at my mother, but any attempts to divert her from my mother is met with violence at me or my father. These periods of violence have occurred for as long as I can remember, but have worsened since she went through puberty. The direct period of violence may last from an hour to several hours, but the build up to the violence may occur over weeks. Usually the violence erupts after a long draining period of time where she is angry and unhappy, which is a stressful time in itself. After the violence my sister is usually feels bad and guilty and we all try and move on. Unfortunately the cycle continues and it occurs again.*

*Not happening as much as it was when I was about 5-6 yrs old (4-5 yrs ago). Sister can have up to a 3 hr tantrum/melt down at times currently*

*She will still have aggressive outburst when she is hurting or unable to get her way, but now she is more likely to slam doors and run the punch. It still happens sometimes but not as much. As a kid, her violent behaviours were a daily occurrence.. they would last as long as it took for her to calm down*

#### 4. Medical attention

Only a couple of siblings reported needing medical attention, while another responded 'not yet'. Another sibling wrote the following:

*I didn't need medical attention for physical injuries as I didn't receive them, but my parents never took me to see a counsellor or to a psychologist to recover from the emotional hurt which was inflicted. I would argue that psychological scars are far more difficult to heal than broken bones.*

#### 5. Other brothers and sisters?

Some siblings responded that their other siblings experience aggression too, for example:

*Yes my other sibling is often pushed over, treated badly, emotionally abused and taken advantage of.*

*Yes, constant verbal abuse*

*I have another younger brother - my sibling with a disability doesn't really lash out at other males (my other brother or Dad), I think he is more afraid of them than Mum and I.*

*My other brother is older and he experiences the same.*

*My much younger sister has also experienced aggression, particularly as she is much smaller*

*Yes she does it to my 4 brothers too but mostly to my 14 year old brother. But it isn't as bad to the boys. I seem to be her number 1 victim after mum.*

*On two occasions my older brothers have been present and become involved similarly, in attempts to stop my sister hurting my mother.  
Yes my little sister who is younger than my brother and he hurts her more often than me.  
My brother experienced her behaviours too. But as he is older than us, he wasn't around as often. Because I'm younger than my sis, I copped most of it*

As an aside, some siblings showed compassion toward their brother or sister in spite of the aggression they experienced. They made comments such as:

*I don't like seeing him sad  
Makes me feel really mad and sad  
I feel sad that he doesn't have friends.*

## 12. Service provider survey

There were 46 responses from service providers.

They came from SA 18, NSW 15, Vic 7, Queensland, 3, WA 2, ACT 1

Professions (we have not sought to clarify these, but just reproduced what was inserted into survey) included: Paediatric Social Worker (3), Occupational Therapist (2), Psychologist (7), social work (3), case manager (4), Counsellor (2), teacher, individual and family support, Family Therapist, Speech Pathologist, early intervention teacher, Keyworker, Allied Health, austswim instructor DECD, csw cara, doctor, Community Care Coordinator, Living skills teacher, Accommodation manager, autism inclusion facilitator, Senior Practitioner, Administration, Family Support Worker, Community Development Coordinator, Youth Case Worker, abc, mental health clinician, Early Intervention Program Assistant /Sibling Group Facilitator, sibling support program coordinator, Disability services coordinator, Local Area Coordinator, Family Support Officer.

These professionals came from a number of settings including disability, community, medical, early intervention, mental health, and education.

Of the 46 who responded 40 identified aggression from a child with disability to siblings as a problem. They were aware of physical and emotional harm being done to a sibling.

It was quite difficult summarising the responses from service providers as the input covered such a range of examples. Certainly there were many disturbing stories. Again, as mentioned earlier, most people understand that the child with disability is struggling too and the challenging behaviours directed towards siblings may be due to sensory issues, frustration, medication side effects, and lack of understanding.

Where possible the information from providers was collated to avoid repetition, but the information below comes direct from responses to each of the survey questions included below. Further summarising would have been desirable to reduce the quantity of material but it was thought to be important to not lose the detail.

### **If you provide services to families of children with disability are you aware of families where the siblings are receiving physical or emotional harm due to the behaviours associated with the disability of their brother or sister?**

In response to this question, the majority of completed surveys reinforced what was said by parents and siblings. Many providers said they knew several families where sibling safety was an issue. As one provider said, "This is one family. I could give you another 10 examples off the top of my head without thinking too hard." Another said that when she worked with children under 6, concerns of active aggression towards family members, or self-injurious behaviours from a child with disability was present in about "70% of the families" that she was asked to work with.

Providers mentioned a range of behaviours that occurred on a daily basis: property damage, hitting, biting, kicking, pushing, punching, scratching, hair pulling, constant harassment, yelling,

screaming, and throwing objects at children. Some providers mentioned broken bones, head or other injuries.

The issue of sexually inappropriate behaviour was also raised a few times, especially when the sibling is younger and cannot defend herself. Sometimes this can be occurring with siblings as young as 3. (In this survey the issue was only mentioned in relation to female siblings; we understand that there may also be male siblings who experience this.)

*As one provider said, I run a group for parents of children with a disability or chronic illness. I have many parents that have children with aspergers and autism who are very aggressive towards their siblings and their parents and other children at times. The parents are at a loss at what to do. Respite is only available once a week. There is tension in the home all the time and the siblings and parents are unable to relax. Often the aggression will result in bruises and/or broken bones in the sibling.*

Providers reported that even if there is no actual physical harm, there can be a range of emotional impacts. Siblings may live in fear of an outburst. A sibling may exist in a constant "fight or flight" mode that will result in their own developmental delays. Some siblings worry and get upset when they see their mother being assaulted, and fear leaving her on her own. Some siblings become very submissive, and do anything to placate their aggressive brother or sister. Some siblings show high anxiety levels; one sibling manifested this by constantly cleaning up and tidying the house. As well as anxiety there can also be hurt, anger and resentment, leading to poor relationships between siblings and between parents and siblings. Siblings may withdraw, develop low self worth and/or develop depression. Providers also mentioned emotional harm to a sibling from just feeling overlooked, neglected or needing to be too responsible for their stage of development; feeling isolated from their peers as their life is so different as a result of having a sibling with a disability; feeling guilty about mixed emotions.

One provider reported that, a 6 year old said, "My name is 'Dave' (false name). I am 6. My sister has a brain problem. She hits me every day says rood [sic] words and hurts my feeling. Nearly every day [I am] crying." This young child, like many siblings, cannot have friends over from school. He feels very different to his peers. "His teachers noticed when he first started school that he was hyper-alert and startled easily which gave them cause for alarm." Also, the issue was raised that some siblings are bullied at school because of their brother or sister's disability so they may be fearful there too.

Another example included "a family with a brother with a mix of disability and depression who is extremely aggressive, explosive, verbally abusive, relentlessly attention seeking, mother loses ability to cope, sinks into depression and overwhelmed by persistent challenging behaviour and aggression, siblings impacted emotionally, they stay awake all night and sleep all day in order to avoid violent brother. One sibling has developed encopresis – in part due to the fear of having to go out of his room but also due to internalising anxiety. Everyone lives in fear. The other sibling is extremely overweight through hiding in her room and eating. She feels trapped and is depressed."

Providers reported that some young people with disability do not have a sense of privacy and this can cause some concern especially by girls when a brother comes into their room and will not leave. Even if not hurt directly they can feel very threatened, especially if the brother is bigger.

Resulting actions by families were also varied, including: parents locking siblings in their room (sometimes overnight), siblings locking themselves in their bedrooms, or parents locking the child with disability in a room. Siblings may be afraid to be left alone with the child with disability.

One provider talked of a sibling who said it was impossible to lock themselves in a room as the child with disability “opens the lock with a knife and then the door is open and he has a knife”. Some families have attached pool fences and gates within the home and extra locks and bars on windows and doors. Some families send siblings to boarding school for their own safety. Or sometimes the child with disability has been removed from their parents care due to the danger they pose to their family, e.g. siblings needing to receive medical intervention after being assaulted. Some families have felt it necessary for the siblings and one parent to move to another residence to prevent harm to the siblings.

Some siblings also worry about the wellbeing of the child with disability, especially when they say things like they don't care if they die and especially if the child with disability is doing dangerous things.

Several providers said that in general families in this situation often lack resilience. They have tried to manage without support and their tolerance becomes depleted. Family relationships break down and families reach a crisis point. Siblings not only experience the aggression and family stress, they can also feel neglected by their parents. They may miss out on social activities because of the behaviour of the child with disability, which adds to their isolation. Also, providers talked of parents, especially mothers, feeling huge doubt about whether they could protect a child, especially if smaller and younger. In some cases families talk of relinquishment, i.e., giving up the care of the child with disability to the State.

### **What action, if any, did you take in response to the aggression?**

Most providers talked about trying to find more respite for families. More directed actions included:

#### *Approaches with parent(s)*

- Counselling regarding parent well being, self care, emotional management, understanding own upbringing and impact on parenting, impact of marital issues
- Listen to the concerns of the parent who feels overwhelmed and not supported.
- Validating, supporting and working with parents to build up capacity to cope, parenting strategies, setting boundaries and how to reinforce them, behaviour plans and routines, safety plans for mum and for all the siblings for the times when explosions happen
- Talk with parents about what is working/not working.
- Psycho-education regarding child's behaviour, stress cycle, development, behaviour modification, family dynamics, how to talk to siblings.
- Work with school on strategies at home and school.
- Look at strategies to address the challenging behaviour, environmental adaptations, sensory approaches, attachment and play based approaches, counselling and support for family members, modifying the environment, parent up-skilling, respite programs .....each intervention is different.
- Referral of parents to Signposts parenting program
- Develop strategies to prevent situations from occurring
- When they do occur, provide parents with strategies of how to manage the crisis as it's happening - separation, diversion/re-direction, debriefing with siblings
- Relationship building opportunities eg increased quality time with sibling(s)

#### *Approaches with child with disability*

- Referral to a psychologist who could look more closely at routines, behaviours etc of child with disability, behaviour intervention/support.
- Supported the family to have a thorough medical assessment to ascertain other issues for the child with the disability eg there was a change in medication.
- Referral to Family Planning Association re inappropriate sexual behaviour

### *Approaches with sibling(s)*

- Sourced sibling support groups, offered sibling websites, sought out a camp for the sibling to attend, other community activities for siblings.
- Provided support, advocacy and therapy for the older sibling, including avoidance strategies, ways to recognise and avoid trigger situations.
- Helped siblings to talk about it and problem solve – some providers have used booklets for this purpose, encouraging siblings to share the booklet with parents.
- Encouraged to talk about it with parents and other trusted adults.
- Encouraged to identify a safe space (may be a locked bedroom)
- Engaged siblings through books that tell stories of other siblings; one young sibling wants to write his own book.
- Referred siblings to counselling with a Family Mental Health support service, psychologist or psychiatrist.

One provider talked of a situation where behavioural intervention services were put into place for the child with the behavioural issues, but also direct therapy was offered to the elder sibling, who in addition to frustration at the physical aggression shown towards himself, was also feeling a sense of responsibility to protect the youngest sibling from his brother's aggression, resulting in high levels of anxiety and strong resentment towards his brother with the disability. Direct therapy gave him strategies to ensure that he felt less responsible, and together with education for his parents on the impact that his sense of responsibility was having on his emotional well-being, assisted the young boy in coping with the situation. Also, "being heard" reduced his level of frustration with the situation. And once he was "given permission" to hand back the responsibility to the parents rather than feeling that he needed to protect them and a younger child, the relief was obvious.

As a provider said, "Sometimes we do sibling work where we explore being a sister or brother instead of trying to be their parent etc. But it's often difficult to address when parents often rely on the siblings for not only physical support but also emotional support".

Providers talked of having limited capacity for follow up with siblings, as they are not the focus of the agency. They also discussed how some parents are very aware of a sibling's need for safety. In other families this is not the case and more drastic action has to occur, e.g. foster placement of the child with the disability if the family violence is too great.

### *Outside intervention*

Some providers said they made a report to the department of community services or child protection agencies - in one case the aggressive sibling was removed into the care of the father so that the siblings could have some respite to recover from years of witnessing and experiencing violence and intimidation.

Sometimes, a number of other approaches were tried first, but the child with disability was still placed in Community services care.

One problem raised was that if notifications are made to the child protection agency and, if they know that another service is involved, they often assess the risk as reduced, so do not tend to become involved. Sadly the aggressive behaviour is not easily changed.

Providers have also suggested parents call police when the behaviour escalates.

**In your professional capacity, do you have suggestions as to how this issue might be addressed, to assist the person with the disability, the sibling/s and the whole family?**

### *With families*

Several providers mentioned that whilst the focus of attention was the child with disability, there needed to be more focus on the whole family, especially in relation to siblings and

especially in regional areas. Often early Intervention offers skill building to one carer only, generally mums, but it needs to be for the whole family.

Several providers said that action needs to be taken before the family gets to a crisis level, as when they get to this stage, the situation can overwhelm them very quickly and they can be beyond receiving assistance – siblings can suffer hugely in this situation. There needs to be more funding for and awareness about preventative strategies.

Families need help to acknowledge that it can happen and it is OK to see it as unacceptable, not just put up with it. They also need an opportunity to acknowledge the ambivalent emotions that can result.

Providers conceded that for children who have a severe condition this can be a very complex problem. It cannot often be solved by a simple behavioural strategy. There can be other factors in play for the most severe cases including the need to have very intensive therapy and support for the family. Other complicating factors may include mental health issues for parents; families where there are one or more children with autism; single parents; grandparents as carers.

Providers said they need to be able to re-direct families to services which can give advice/education to help with the aggression and challenging behaviours – to education parents and siblings how best to respond and take themselves away from the situation if required. Providers highlighted that families need skills to build capacity and confidence when managing a child's behaviour. They also need emotional support from somewhere that understands their situation and can listen and discuss options without judging them. They need community support as they are very isolated from the community because of their child's behaviours.

Providing respite was the most prevalent action and recommendation from providers. For example, "Families need a break in order to build up their energy to keep going, having a few hours on a Saturday morning is almost a waste of money but families take it because it is all they are being offered, I believe if mothers could have a break of a few days every month or fortnight, they would be able to keep going, the siblings would have a break, be able to bring friends home for play dates, relax and have some of their mothers attention, and I believe that this would completely alter the outcome for ALL concerned. Respite needs to be flexible; professional support in the home can be useful."

Some providers mentioned that the more intensive services which are needed are not available in Australia. For example, a live in intensive situation in which the family could be provided with day to day support on interactions with their child was mentioned a few times. "We have many suggestions, but not all can be employed within current systems."

#### *With child with disability*

Providers suggested a number of strategies to be used with the child with disability, for example:

- Closely observe and document routines and what is happening before, during and after the behaviours including any changes in routine, unexpected contact with others, different foods or medications.
- Try to determine any patterns. Identify the client's sensory preferences to determine if these are contributing to the observed behaviours. If possible, educate the child about the outcomes of his/her actions.
- Funding provided for specialist intervention teams that have the time and capacity to address the complex nature of challenging behaviour and who have the training to understand that challenging behaviour serves a communicative function and that we need to ascertain what function it serves for the person and how to provide a more appropriate and safer way to meet that need.

- Developing a behaviour response plan (reactive and proactive strategies) that is part of a broader positive behaviour support program. The aim is always to increase the quality of life of the family and not merely just to 'extinguish' particular behaviour.

#### *With siblings*

Many providers thought there should be more support programs for siblings eg sibling groups. Such groups could also include creative writing or drawing opportunities for siblings to tell their story, allow some healing and create some normalisation. More funding for respite to allow parents time to spend time with their other siblings was also thought to be important.

#### *With providers*

Providers identified that there needs to be more education for professionals who are working with families on how to manage aggression. And standard child protection issues and the discussion of the effects of abuse or violence should be an integral part of all service provider welcome talks. A child's right to feel safe is paramount and this should be reinforced and modelled by service providers.

## Recommendations

Siblings Australia has written a number of reports about the needs of siblings and making recommendations for future activities. Together with Families Australia the organisation developed a [National Action Plan](#) which called for more data collection, research and also more co-ordination of sibling support programs. With regard the issue of physical harm to siblings many of the same strategies would apply. However, directions re this particular issue could include:

- Further research into the incidence and nature of the aggression, including both physical and emotional outcomes
- Further research into what families need in these situations where a child with disability is prone to aggressive behaviour
- Development of pathways of support for families which include approaches with all members of the family
- Workforce development to raise awareness and skills for people working with families who face this issue
- Development of cross-sectoral alliances to develop these appropriate pathways of support, e.g., child protection, disability, health, education and community services

## Appendix 1

### Other comments

There was another section in each of the surveys where respondents could make other comments. These are reproduced below.

#### ***By parents***

Currently seeking therapy for our daughter

Thank you for your work in helping Siblings.

More generalised help needed for families to cope with how confronting this all is

I think that this is a big issue. My autistic child is in the middle of three children relatively close together. I was paying \$200 per session for my eldest son to see a psych - as he was so frustrated and angry with the autistic sibling and needed to learn how to deal with it.

I think more awareness is needed for the siblings of a child with special needs. It impacts hugely on their studies/homework as lots of therapy takes place at home and siblings are involved.

This should be recognised by the education system of children sitting exams.

I moved out of our family home with my daughters for a period until we could get some decent weekend respite for my son. I was extremely concerned about their emotional wellbeing and them having to tolerate the level of aggression they were being subjected to on a daily basis. My young daughter got to the stage when she would not come out of her room in the morning and wanted to eat meals in her bedroom. She actually asked if I could get extra respite for her brother. While they love him dearly, they thoroughly enjoy the weekends now when they are able to fully participate in "normal" activities as a family.

More should be done to help families

My younger daughter has already experienced depression and looks as though she may do again.

More awareness of the issue for siblings who are in this situation to encourage siblings to be supportive and to normalize disabilities so that the non-disabled siblings do not feel ashamed or resentful of their sibling with the disability

I am deeply concerned for my daughter (sibling). She is only 5 and already gets very emotional and has difficulty with emotional resilience. She does not understand what happens to her because she does not understand yet that her sister is really different. I have tried to broach the subject at times when she has been really upset but the concepts do not register with her yet. Having said that they are actually good friends and if either of them is in trouble the other will quickly spring to defend their sibling. I am really looking for fun workshops that she could do to help her adjust to the situation she is in. She shouldn't have to learn to just tolerate life.

We are still in early days; learning that the word "ow" is a cue to stop. Fingers crossed.

Sibling aggression is very hard to protect the victim and is extremely hard to stop.

The inflexibility, relentless demands and anger drains the whole family and takes away some of the parental emotions and times from the other sibling and partner and any other relationships you have left - if you have any.

Because these boys (with disability) struggle socially, they become overwhelmed and frustrated faster than most people so they tend to react (without thinking). As parents, we work hard to notice the signs and assist with emotional and physical regulation. It's hard, but we persevere. It was the worst period of my life! To this day I do not know what changed him back to being friends with his sister. It was almost like hating her became his obsession and once he had moved on to a new obsession he could let the old one go. My daughter still has emotional scars and feels sad that her brother doesn't love her even though they play together again and happily sit alongside each other. I hope that over time this will heal.

I contacted parent help line and referred my Aspergers son to Psych because he forced his younger brother (3 yrs) to drink his wee.

This is a very important survey - thanks for the initiative

We have tried to teach our other children to protect themselves by looking for the early signs and moving away. I think this is the only reason something more serious hasn't happened to date.

Having real agencies to help would be great it seems there isn't any really

Siblings Australia is a fantastic initiative and I wish the govt would fund it more, cos the siblings are the ones that suffer the most :(

We treat all our children the same. We have expectations of all of them and give each of them individual time. We have explained to the elder child what aspergers is and how it affects their brother and so that he is not getting special treatment but is being treated at the age at which his brain functions in those areas.

I (the mother) believe one of the greatest problems my daughter is facing at present is that when my son is at home she is on edge most of the time, never knowing when / if she will be screamed at or have toys snatched off her etc. It is amazing the difference in her when he is not at home. She is more relaxed and happy.

It is a very distressing issue

We need more sibling support outings/sessions.....

Living with three children on the spectrum who are all so different is very hard. My daughter in particular knows her family is very different to her school friends and has suffered a lot from what her brothers have gone through.

My son became disabled at a young age and his sibling was a few years older, it was an extremely difficult situation and there was no help back then, 11 years ago which I could access for my daughter (sibling), it has left her with a huge emotional chip on her shoulder (that is the only way I can describe it). As parents we did the best we could for both our children but it has impacted our daughter's life in a major way that has caused her to leave home and not have much contact with us.

Thanks for following up on finding out more about this issue it is a really challenging one for us. It is hard for the sibling she believes that having a brother with aspergers is the worst kind of brother in the world

We need to be able to access support for siblings as a matter of urgency. They feel left out, second best and often unloved. They bottle their anger up and become the unwell of the future. Parents feel guilty because they feel like they've let their other children down.

I am scared that eldest son will hurt sib. I have been doing weight training to make myself stronger in case I need to break a situation up. But the sib does needle his siblings often till they get to meltdown and I need some strategies to help sib learn not to needle the others for his own safety and my sanity.

Both children are very close and his sister is extremely nurturing towards him. They both adore each other. The biting or pinching has usually been over a toy or during a frustrated outburst. We are working on his aggression and sometimes it is not as bad particularly if I am in the room. I am too scared to really leave them alone together (even to go to the toilet).

Children with autism aren't usually aggressive they are just misunderstood.

95% of the time he is gentle, 4% he gets verbally abusive and 1% he wants to hit something. We introduced a punching or boxing bag and he goes outside now and hits that until he calms down. It works for us.

My daughter also grew up with a brother with ADHD two years younger than herself and found both physical and emotional challenges during childhood years.

My daughter often lashes out at her sister because she is the closest one - both in proximity and emotionally. Similar aggression towards her parents. Usually happens out of frustration (with her own limitations) and jealousy (of her sib being able to do more and having more friends than her).

I can see how deeply this affects our daughter. She is quite distraught over this.

Interesting topic and thanks for organising it.

I'm so sorry for my daughter for the years that was worse and I can't get that back.

Different parental approaches to the problem have caused my husband and I to separate. I am also the target of older son's aggression.

It would be great if there was assistance or support that is easy to access. We are currently waiting to see a paediatrician and have to wait 4 months - this was after numerous calls to doctors who were full. So sad to see my elder daughter afraid of my younger daughter and the aggressive behaviour escalating in my youngest - no idea where else to turn for help so we end up isolating ourselves from friends and family.

### ***By siblings***

What I have described is not unusual in regular sibling relationships. My sister is temperamental, moody and emotional; I am calm and controlled. If she didn't have a disability yet had this personality, our relationship would likely be the same. There is not necessarily a causal relationship between her disability and outbursts, though it's fair to say one may exacerbate the other.

he wants me to do everything he says. he has tantrums over nothing. he annoys me.

It is horrible :(

Sometimes I wish my mum can give my brother away.

I have to give her everything she wants

I guess I'm just used to the way he is  
Friends and other people never understood how scary it could be to be targeted so much, especially when we were teenagers. Others also never understood that it was more than sibling rough housing. He never understood his effect on me and wouldn't be told off by my parents as he didn't understand or was not in his right mind.  
thank you for asking about siblings and impact on them. i fear no one else can understand.  
Parents need to be educated about the impact that psychological bullying by disabled children can have on able-bodied siblings, especially as the able-bodied sibling is forbidden by the family from ever retaliating using physical force against the disabled child.  
The behaviours were related to communication difficulties and during tantrums. Once positive behavioural strategies were implemented consistently, and more appropriate ways of communicating my brothers frustration were explored and taught to him, the behaviours significantly decreased and are now no longer a major issue.  
My life choices were affected by having a brother in the family with a disability. I have never recovered really. I just try to live with it. The abuse was never validated by my parents.  
Mum cops it more than me, but I hope my answers are helpful for the survey.  
Mum adds bigger sister did cop alot of hits when she was living with us, and asperger boy was younger. Hit with toys mainly being hurled.  
thank you  
I love my bro  
Make other children aware of the problems these kids have through schools etc.  
I love my brother and I know he loves me but I just wish he wouldn't be so mean and hurt me and tease me all the time. I wish he could be proud of me sometimes instead of angry because I can do stuff he can't even though he is older than me.  
Thanks for caring  
Is more of an issue with my parents.  
My sisters anger stems from her jealousy of my life, that I have everything that she wants such as a partner, children, house, car etc.  
Her behavior makes me very frustrated and sometimes I feel that no one understands. I feel like I'm not important and mum doesn't give time for me or my brothers. I know it's hard for her cos she is a single mum and she is trying her hardest to do wots best for everyone. My sister always tries to take her own life and mum just has to drop everything and run. Sometimes she stays at the hospital with my sister and waits for her to come out of a coma when she has overdosed.  
My brothers have to look after us younger ones (more so when we were younger) and this makes me sad that my mum is not there for us.  
It is a particularly difficult situation for our family. We love our sister /daughter, but find these periods of anger from her distressing. It is not something that is openly discussed with our wider family and friends and creates a significant burden. To outsiders she appears happy and amiable. During these times we have difficulty working out how to handle an aggressive adult, and have threatened to call the police but aren't comfortable with this approach. We have considered the need for mental health involvement, but working out how to get her to cooperate and attend such an appointment is beyond us at this time.  
If we could get free or cheap respite so could spend time with mum  
If I want to talk to someone about issues I call Kids Helps or talk to Mum or Dad. I feel that my parents listen to my concerns most of the time.  
Unless a person has lived with someone with a disability, no one will ever truly understand the depth of hurtful behaviours that occur. Everyone's story is different and that is an important thing to remember. Each family member will have different experience, different grief. My life as a SIB has shaped me for who i am and despite the hurt and the toll it's taken on my life, i wouldn't change it. Instead, I will use my experience to help others.

***By providers***

Keep up the great work – thanx 4 ur help

There are not enough sibling groups and often there are waiting lists or they don't cater for younger kids. Thanks to Kate Strohm for all her hard work in this important area!!  
Some services are able to provide Medicare services for people with a disability and their families to deal with both behavioural issues and the impact on the family.  
Thank you for doing such a great job and we hope you can continue to do so.  
Thanks for your work :)  
Thanks for putting this survey together.  
Great to see Siblings Australia put forward another important issue. Well done!