

Family phone-in re sibling support January 12 2013

Independent Senator Nick Xenophon, a strong supporter of Siblings Australia, provided his office for a day for us to conduct a 'phone-in' regarding sibling support. We asked families: What are the challenges for siblings? What support have you accessed in the past that has been useful for your child (if you are a parent) or for yourself (if you are a sibling)? What specific support would be helpful for siblings eg peer support, counselling, school support etc?

People were invited to call the office number on January 12th OR post a comment on the Siblings Australia Facebook page OR email their thoughts by email to kate@siblingsaustralia.org.au

The following comments came in via direct phone calls, emails or comments on Facebook. All of the comments received have been recorded; some have been joined together or condensed. Most of the comments are from parents except when they are identified as being from siblings. Direct quotes are in italics.

Challenges

- when a diagnosis is made there are so many mixed feelings – *my son, the sib, bore the brunt of our grief as a family when the diagnosis was made*
- Often parents spend more time with ASD child as they require more support and the siblings can feel left out. This may lead to anger or the siblings just removing themselves from family and community. *I feel that often siblings are referred to as the ASD child's brother or sister when going places; the sibling seems to have their identity lost and taken over by their ASD sibling.*
- Life revolves around child with disability. One parent said her child's after school time was always spent going to appointments etc for child with disability and because they lived in a regional area that meant lots of driving to the capital city
- Sib is often asked to chase his brother, especially in public if his brother runs off. This causes huge embarrassment and sib says *I wish I didn't have a brother with autism.*
- The responsibility can become too much
- An adult sibling said she was not able to spend time with her parents due to time constraints, there were financial pressures always due to the medical needs of her sister and there was a lot of family disruption due to hospital visits etc.
- struggle with creating satisfying, mutually supportive friendships (lack of understanding by others of sib issues)
- Some parents mentioned the unwillingness of siblings to bring friends home
- a couple of parents mentioned that siblings struggled at school, not only with friendships but also with keeping up with their schoolwork. Another mentioned that fact her child was often called on to be a 'carer' at school.
- *Struggled socially and was teased a lot at school due to his brother's disability. He didn't bring friends home. He had no childhood. And now at 16 he wants to leave home.* In this case there is some consideration being given to relinquishing the child with disability.
- child with autism not able to attend same school as brothers and so there has been quite a split in the family
- Older sister in late teens with disability, two younger sibs are both needing psychological support – very expensive but it is very necessary due to the ongoing stresses for sibs
- outings (community activities) can be difficult (due to cost, support care for child with disability not available)
- Family cannot go on holidays
- Often couples fight a lot due to the stresses of raising the child with disability and this can upset sib
- Often couples break up which adds to the difficulty with split homes etc – and housing can be difficult

- Sib is getting to the age where he's involved in lots of activities (bowling, football) – the family would like brother to join in but this has two difficulties. Firstly, sib feels like he can't do anything by himself and secondly brother not physically capable of joining in some of these activities.
- Sib feels isolated because he never sees a family where there are siblings of children with a disability.
- Parent said *I wish I wasn't so exhausted, there is so much to tell ... sibling issues are as huge as the issues related to child with disability, as it turns out. All sorts of things have happened over the years ... I am so stuffed myself ... it is very tough for the siblings ... the sibling here is now 17, almost 18 ... lots of things*
- Can be physical harm sometimes as well as emotional eg the child with disability does not necessarily understand what they are doing. One child had her leg broken when the brother had become too boisterous; she is also repeatedly scratched.
- Various disabilities can cause huge frustration in the child and they might lash out eg *when she was tiny she was an habitual tantrum thrower, once she could walk etc she used to smack me (the sibling) and kids at pre-school and then when she had bad tempers and episodes through her teenage years she had some physical aggression*
- Sometimes complicated when the sibling has a minor disability so even more difficult to access support groups.
- Sometimes siblings are 'young carers'; on the other hand some families do not like this term even if the sibling is helping out. Some siblings do not provide any care to the child with disability.
- Sometimes a child with disability is sent away to an institution and this can result in other challenges eg guilt, not being able to see the child in some cases and not understanding what has happened
- Parent concerned about how the boys will be as they get older, lack of structured support for both brother and sibling as they become teenagers (emphasis seems to be on intervention in early years)
- Things change as both the sib and the child with disability move into adolescence as hormones kick in and they get bigger and stronger
- Some siblings show a certain amount of bravado ie they say that everything is fine but one parent talked about how when she spoke to her son about the phone-in he admitted he had left home last year at the age of 18 because of the stress at home. He felt anxious and guilty.
- Challenges last into adulthood, some siblings are providing much in the way of practical and financial support but not receiving any support themselves
- Siblings said that the responsibilities change over time and often increase significantly as their parents age or pass away
- Siblings of people with Mental Illness talked of being 'shut out' – that they were not told, for example, when medication might have changed and so could not be prepared for the changes

Available support

- Many respondents said that there was absolutely no support available, and whilst some from regional/rural areas said it was even worse there, the reality seems that there is very little support anywhere
- If there are programs they usually disappear for teen sibs
- Accessed one activity years ago but not enough
- Two night family camps which we attended twice were helpful until sib was 'too old' for them. They were without the child with disability. Parent felt that it is good to have some with and some without the child with disability.
- Counselling had been a help for some
- Parents talked about there being no support from anywhere and that this has led to psychological difficulties in the siblings – funding has dried up for many services eg there used to be some respite available but that now rare eg 2-3 nights per year – a feeling of being abandoned by the government. Most support is directed to older carers
- An adult sibling said that she had not been able to access much support. She had gone to one sibling event many years ago which she had appreciated as it gave her an opportunity to meet with others – however it wasn't continued
- Another adult sibling (brother) said that when he was younger there was no support and it had been really needed by him. All through his teens, twenties, thirties and beyond he knew no one with a

disabled brother or sister. After his father died and his mother got older he was the primary carer for both his mother and brother until they went into a nursing home. He did not marry until his 50s as his family responsibilities were too great and it was difficult to find someone who would understand.

- One family talked of being thankful for the 2 hours a week domestic assistance that they get which frees up the parents' time so they can spend some time with sibs. There is constant worry that they will lose that. They suggested it would be good if they can use some NDIS funding for this when that rolls out, to give them security.
- Respite needs are different for different families – some need out of home care and others need more in-home assistance. Should be more individualised.
- Has been to a family day run by a carers network but sib is quite shy around large groups of people
- An adult sibling who is now providing support to her sister said she is not aware of sibling services
- Some siblings talked of not having a voice or any sense of their own needs eg *Until I read a newspaper article and the book 'Siblings' I never realised that I had or was allowed to have rights in this relationship and have spent most of my life feeling bad for being born without disability.....it is a huge burden for any sibling to have to carry throughout their lives and then when their parents die to have to become the primary carer and look after their family.*

What would help?

Many parents and siblings wished there was more support available. As one mum said, *Siblings often feel left out and carry extra responsibility, wouldn't it be fantastic if we could acknowledge this with appropriate supply and funding. Groups for siblings to share their story, have time out and learn more about issues they face, let's give siblings a voice and someone to listen to them and support them on their long journey. I am thankful everyday for the gentle caring sister my son has and her ability to understand his needs.*

Below is a summary of the points made during the phone-in and through emails etc

- Peer support

Many parents said that peer support sibling programs would be the most useful thing for their children, in order to help siblings to feel they are not alone. The programs needed to be from a young age. Some added this needed to be combined with professional support, to guide some discussion. Adult siblings also said that peer support would have been helpful as children. *Not that I ever had any but is the number 1 thing I would have appreciated*

One parent said the peer support had helped her child so much. It enabled her *to have fun, forget about some of the everyday responsibilities of being a sib of a brother with profound multiple disabilities, and given her valuable friendships. It is the extra opportunities to meet socially outside of formally organised and funded events that have made the difference; some of these events are family events so she meets the sibs with disabilities too are has an enhanced understanding of what their needs are and the challenges that their behaviours and disabilities may promote in the family.*

Funding/initiatives which support family driven/peer supports were seen as vital...anything which makes it easier for time and energy strapped family members to organise and meet at outings. This was a recurrent theme ie that families are exhausted and it is very difficult for them to get out and organise support or community activities

Several adult siblings wished there had been peer support as a child, as part of fun activities like camps, day activities etc, but also wished there was peer support for adult siblings eg coffee catch ups. They wish there were more services for siblings to access, both for emotional support but also to find out more about services for their brother or sister. An adult sibling (brother) said he would suggest peer support groups, counselling, school support for younger siblings and a support and social club for older sibs where they can organise activities amongst themselves and get out together away from their circumstances for a few hours or so, maybe even camps. He added that siblings, like carers, need a break from time to time and some respite organised for their sib who has the disability.

A sibling of someone with Mental Illness said, *The types of support I would have liked when younger would have been having access to more education about my sibling's condition, knowledge on how to support them and myself around living with a sibling with a Mental Illness. Also time out to spend with other siblings at camps etc. As an adult I think peer support is a great asset and also access to information.*

The idea of using technology to connect was also raised, but it was also felt that face to face time connecting at a deeper level in 'real life' was also important

One parent mentioned that a program like the Smiles program run by Arafmi in WA would have benefited both her sibling children. The program helps children to understand mental illness and how it impacts the family member's behaviours. It can help to answer questions and fears. She felt that something similar which allowed sibs to address similar issues related to disability eg information about the disability and the impact on the whole family, health and wellbeing strategies for the whole family, what might happen in the future etc, would have helped sibs a lot.

Small gatherings of siblings so sib has a chance to see that he is not alone

Assistance to help sib cope with embarrassment etc eg counselling, peer support

- Counselling

One parent said that her child who is a sibling is now a young man, and he now says that he needed counselling, more information about the disabilities his brother had and how they would impact him physically, emotionally and intellectually as he grew older. He also wished there had been greater awareness of the issues he faced as a sib by the school community. He did his best to hide his other life because that's what he wanted as a young teen, but as an older teen he can see that school could have encouraged him more to use some of his talents and insights and to participate in extra curricula activities. One of the reasons he didn't participate in extra curriculum things was because he knew it made it harder for his mum to manage after school and because he was reticent to take on more in his life. The parent had tried to educate the school psychologist, who was very open, about sib issues when by the latter years of high school he was experiencing anxiety issues which have continued on and off since then.

A sibling whose sister was sent away to an institution said that she would have liked counselling at the time to explain what was happening and to allow her to talk through her feelings etc

- Special programs for siblings

I would like to see scholarships or 'internships' or some special opportunities for sibs to develop their own talents/aptitudes/interests...doesn't need to be academic, could be sporting, cultural, film making, art...big and small...and opportunities for sibs from around Australia to meet and share their ideas/interests...little 'fringe' type gatherings.

- Time with parents

What siblings are crying out for is precious, quality time with a parent who's not attending to the high needs of the siblings at the same time. Kids aren't stupid, they know when you're talking to them if you really are giving your attention or standing there, worrying cause you haven't seen the one with a disability for five minutes, i.e. is he shoving toilet paper down the loo and blocking it? Has he found the missing panels in the back fence and wandered off to a nearby dam? Has he wandered up the road? and so on, and so on...We need better trained support workers, more dollars to be able to employ them with a view to freeing up parent-carers so they can spend dedicated time, albeit once or twice per week with the other siblings, who deserve so much more.

- Support needs to be across ages

Several parents stressed the need for sibling support from a very young age and that support was needed for the whole family.

Most programs (if you can find one) don't start until they are 7. My 4.5 year old's emotional intelligence is quite high and she knows my son has higher needs than her and just deals with it. But peer support would help and so would more/improved respite so families can 'have a break' not just to catch up on sleep/shopping/mundane life but to enjoy the other children they have!

Other parents stressed the need for specific sibling support for older children as well, not 'young carer' programs but specific ones for siblings. Often the teen years have a whole lot of other pressures too and being a sib just adds to that.

Adult siblings often need information about what services are available to help them in their role as support person to their brother or sister – both practical and emotional support

- School based programs

Some parents said that school based support could benefit a lot of siblings, so they could share the pressures they have with others in the same situations. Others said that schools needed greater understanding of the

issues for siblings and how this can affect their schooling. One parent had talked to the school at different times about the effects on her child of being a sib. For example, if the child comes to school upset and teary the parent has explained what the cause has been eg a meltdown by the child with disability on the way to school. This parent has also expressed to teachers her wish that the child does not become a 'carer' at school for her brother or other children

- Parent support

Many families have parents who split up and so the father is not around much. There needs to be more support for the couple to manage the different stresses together. Initiatives that support the parents' relationship (whether 'together' or not) are important in giving safety, security, etc to the sibs in the family. It is important too for extended family and friends to be helped to understand and support the family.

- Mentoring programs

Without a father around much, some sibs, especially boys, really need a positive role model to help him deal with conflict and aggression more positively. Several parents mentioned the need for mentoring programs, regardless of family structure. *As a young teen my son was introduced to some older teens who'd left school and were developing their careers and this helped him to see a life beyond the 'hospital like' environment of our home*

Another parent suggested mentoring from older sibs eg a 'sisters day' where older sibs could get together with younger sibs and do 'girly things' – would provide contact with an adult who understands.

- Services for child with disability

One person thought the best way to support siblings would be to *let their brother or sister have access to education and health care*. A parent added that *there is no coherent, well planned strategy or formal acknowledgement of the needs of sibs. I hope the NDIS entrenches this in its entitlements to services and supports.*

The following is an email from an adult sibling, received as a part of the 'phone in' and reproduced here in its entirety.

My older brother was born with an intellectual disability from head trauma and lack of oxygen at birth. My mother was in labour for 3 days and said his head was bruised and caved in looking when she first saw him. She would cry every time she saw a baby being born on TV. I was angry for years at the doctor who delivered him; that he didn't do a caesarean so my brother could have been normal.

When I was born my brother with a disability was already 7 years old, strong and volatile. I was scared of him. I grew up walking on eggshells in case a comment would set him off yelling and throwing things. He once threw out my pancake batter I had been resting for half an hour, I wasn't happy with him so he hit me over the back. He cut the hair off my dolls, constantly snapped books shut I was part way through reading and tore up the monopoly cards and threw them behind the wardrobe, the list goes on. From when I was 1 or 2, he stayed at a special school in a nearby town from the farm I grew up on and only came home during weekends and school holidays. Every time he had to go back there was a drama, hiding clothes, shouting, jumping up and down, shouting 'no no no' he didn't want to go, it was awful. He went away during school holidays to stay in Perth from age 14, I couldn't wait for him to go each time and dreaded him coming back yet felt incredibly guilty when he was away. A couple of years later my parents sent him away to live in Perth (in a big old house that looked like a haunted house to me) all the time, because of some inappropriate behaviours that were impacting on me.

I noticed much later on my primary school grades started to improve gradually from the time he went to Perth to live most of the year. The grief from my mother was tangible and I absorbed it like a sponge. No one spoke about how they felt. I asked Mum when I was younger couldn't he just stop being like he was, I clearly didn't have the emotional maturity to deal with what was happening so I used to fantasise that one day he would just stop and be normal and it was all just pretending. In all my dreams about him he was normal and we had normal conversations, in real life he had a severe stutter, would speak maybe 3 words at once and I had no idea of what he felt or thought about anything only through his actions, which reflected misunderstanding and frustration, he could not be reasoned with. He used to wet himself in public which was embarrassing for me.

In my late teens I started to self-medicate with alcohol. When I got drunk when at Uni I would often cry and cry about my brother; I was incredibly anxious whenever he was around and couldn't stand the thought of being near him or him touching me. Although I am a high functioning adult who has gone to University and had a great career this habit of self-medicating to deal with anxiety has become a lifelong habit. When I got married I was terrified of the thought of having a baby in case it would have a disability, I didn't think I could handle that and may even reject the child and so I remain childless. Now in my forties and in a better place, I wonder what might have been if I hadn't felt that way. When my mother died suddenly 13 years ago my father handed the reins for my brother to me; he has never been able to cope emotionally with my brother having a disability. I had years and years of counselling from a psychologist (which cost me thousands of dollars that affected me financially) and I am not sure if it was that or my brothers eventual physical deterioration (meaning that he felt less like a threat to me) that enabled me to finally become the part of his life that I am today.

I often wonder if there had been some intervention, counselling, peer support, for me could it have saved me the bottled up anguish I carried around for over 30 years. If the government does not make this a priority I worry for not only the people with the disability (whose siblings will have the longest relationship with them and need to be in a good place to support and advocate for them) but the legions of children damaged in their wake and destined to take this dysfunction into their adult lives and relationships.