

The National Framework for Protecting Australia's Children 2009-2020

Protecting children is everyone's business

Developing the Third Action Plan (2015-2018)

Driving change: engaging the community

Response by Siblings Australia to the Discussion Paper

I am pleased to present the following response to the Discussion Paper: Developing the Third Action Plan (DP), on behalf of Siblings Australia (see later for a discussion on the organisation and its work). The basic premise of this submission is that siblings are not recognised by governments and the community as being 'at risk'. They are nowhere in policy or programs. If this current Third Action Plan cannot address the needs of siblings of children with disability, then the Plan should be highlighting the gap to relevant government Ministers and departments eg families, disability, health and education. Through this submission the term 'disability' will be used but siblings of children with chronic illness or mental illness can also be at risk.

This submission will include the following:

1. Gaps within current Discussion Paper
2. Answers to discussion questions
3. Why siblings of children with disability are at risk
4. Siblings Australia
5. Recommendations

1. Gaps within current Discussion Paper

It is encouraging to see that work is continuing on the National Framework and specifically on developing a Third Action Plan. However, Siblings Australia would like to highlight some gaps within the draft Plan.

Under the heading 'Focus Areas', the DP states that the actions under the draft National Priorities 'will need to consider the diverse needs of different groups, and work towards addressing unique risk factors'. There are significant gaps in understanding and practice about what constitutes risk factors and what 'abuse and neglect' might look like. The focus is still very much on physical violence and neglect, with less attention given to emotional effects on young children, or keeping children safe and well.

Also there are gaps in relation to the groups of vulnerable children, both in their identification and in support services. Under the heading of Focus Areas the DP states that the 'Third Action Plan will also consider the unique needs of families where disability is impacting upon the parent or the child, acknowledging their over-representation in the out-of-home care system'. This totally ignores the impact on other children (siblings of the child with disability) in the family, whether the child with disability is living at home or in the out-of-home care system.

Whilst most children who might be seen as 'at risk' have policy and programs targeted at their needs, siblings of children with disability are not recognised at all in either policy or programs. The only organisation in Australia that has a focus on siblings has not had funding in the last 8 years of its 16 year history. This is in spite of a national and international reputation for its work.

1. Discussion questions

1. Do the five draft National Priorities effectively capture the critical focus areas for national collaboration?

Again, there are gaps. National Priority 1, 'Strengthening universal and early intervention supports for at risk children, young people and families', implies that there are services available to be strengthened. For most at risk children this is the case. Of course there may not be enough or effective services, but there is recognition in relation to most vulnerable groups both in policy and programs. However, there is no policy or programs in relation to siblings, apart from a few provided by committed individuals.

There are no resources put into a national approach to sibling support. Siblings Australia has tried to collaborate with a number of agencies re the needs of siblings but there is still a lack of awareness about the needs of siblings. Siblings Australia is a lone voice and without adequate resources it is difficult for the organisation to engage effectively with other agencies, especially given that few agencies see siblings as being part of their 'business'. Some agencies have even suggested that we need to realise that it is a 'competition'. Similar responses come from government, with Siblings Australia being shunted from department to department with the claim that it is another department's responsibility. No one government department will take on responsibility for this group. In order for siblings to be properly recognised through the funding of a national initiative there needs to be more agencies who advocate on their behalf.

National Priority 2, 'Empowering communities to keep children and young people safe and well', implies that there is understanding and awareness about the needs of siblings. Some of the material directed at either siblings or parents is less than desirable, even from very reputable agencies. It highlights the lack of awareness of the issues and needs of siblings. Such approaches do not draw on 'best practice' principles. There is a lack of awareness that collaboration is needed in this area, especially with the most experienced agency ie Siblings Australia.

National Priority 3 & 4 have the same issues as above ie a lack of capacity for Siblings Australia to take part in any collaboration and a lack of awareness by other agencies that collaboration should be happening regarding the needs of siblings. I cannot comment on National Priority 5.

2. Do the five draft National Priorities effectively capture the key focus areas for early intervention and prevention?

Some of the big issues faced by vulnerable children are not readily addressed. The situations can be very complex. Whilst the situation with siblings can also be very complex, early intervention and prevention can make a huge difference to how the sibling copes with the stresses.

Intervening with the other 'settings' in which a sibling operates also has the potential for big shifts in the way a sibling copes. Peer support can be especially beneficial in this instance.

However, unfortunately, siblings are still overlooked and so would not be captured in the draft National Priorities.

3. Are there any key focus areas which would benefit from national collaboration that are not represented?

Siblings are not mentioned under Focus Areas, only the parents and the child with disability. This is a major oversight. Children with disability are certainly vulnerable but so too can their brothers and sisters face challenges. There is strong evidence to suggest that siblings are at risk for emotional and physical harm. See below. There needs to be stronger collaboration between agencies where siblings are relevant, that is, disability, health, community services, child protection etc

4. What actions could be included in the Third Action Plan that focus on prevention and early intervention and require national collaboration to achieve results?

It is imperative that more actions are included that relate to the identification of other vulnerable groups, not included at present

5. What existing projects are you aware of that could benefit from additional national collaborative effort as part of the Third Action Plan?

Certainly, in order for there to be more effective approaches with regard siblings of children with disability, there needs to be additional national collaborative effort put into advocating for siblings and the development of best practice approaches to their support. Siblings Australia has attempted to do this but could do much more if it had the necessary resources

6. How can the unique needs of children from culturally and linguistically diverse backgrounds including newly arrived migrants and humanitarian entrants be adequately considered within the Third Action Plan?

Not applicable

7. How can the unique needs of children and families that are impacted by disability be adequately considered within the Third Action Plan?

If we are to truly consider families and not just parents and the child(ren) with disability, then siblings need to be identified specifically as at risk. There is much discussion about the rights of people with disability, which is well overdue, but these rights cannot be considered without also considering the rights of other family members. Siblings Australia needs to be acknowledged as the lead agency in this area and be resourced to collaborate with relevant agencies. It should also be remembered that siblings often have the longest relationship of any and so any support to strengthen the bond will also ultimately benefit children with disability, and add to their safety and wellbeing. Siblings often become the most active 'protector' of their brother or sister with disability.

8. Are there any additional vulnerable groups that would benefit from an increased focus under the Third Action Plan?

As mentioned, siblings of children with disability would benefit from an increased focus under the Third Action Plan.

Why siblings are at risk

Siblings of a child with disability can grow up in a situation of considerable stress. This stress can be exacerbated if the family breaks down (a higher likelihood in these families) and if the child with disability has difficult or aggressive behaviours.

Whilst some can be enriched by their experiences of growing up with a brother or sister with disability, for many, the lack of cognitive and emotional maturity can mean they struggle to cope. This can have immediate and longer term impacts on their mental, emotional and social and physical health. Some siblings are physically abused by a brother or sister with disability. The report [Sibs and physical harm](#) (2012) came from a series of surveys developed by Siblings Australia for parents, siblings and service providers. It is a sensitive topic, but one that cannot be ignored.

The earlier [Adult Sibling Project](#) (2009) heard from adult siblings of people with disability, and highlighted a number of challenges, impacts on their mental and physical mental health, and unhealthy coping strategies. I urge whoever is reading this submission to read both of the above reports. They are at times difficult to read but they give an important insight into the world of siblings.

Certainly many siblings say that they grew up feeling abandoned or neglected, although many siblings resist saying anything that might seem critical of parents. In many cases, even the most loving of parents are so stretched by caring for the child with disability that there is little left for anyone else. Siblings often feel that their needs are put on the back-burner; they feel invisible and uncared for. Parents may be going through their own struggles, including depression, and be unavailable to able siblings. Some siblings say they felt they were not allowed ever to have problems, and so were left to deal with their issues alone. Not wanting to bother parents who have enough to deal with is a common theme.

I am including some quotes from adult siblings, to clarify this, below. I have not acknowledged where they have come from (my book, *Siblings: Brothers and Sisters of Children with Disability*, revised edition 2014) as the discussion paper states that submissions will not be published. If this policy changes I would like to be informed so I can delete the quotes or acknowledge where they come from.

I was four when the severity of his [my brother's] condition was unfolding. At this crucial juncture, when I needed my parents for my own growth and development, they were drowning emotionally while the severity of Marc's condition was becoming apparent . . . There was little, if any, room left over for me and my problems. I was an emotional orphan.

My mother said to me 'I'm glad you're normal so you can take care of yourself.'

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

I struggle with depression and guilt and anger and grief every single day of my life, to the extent that I am on medication. I abuse my body by overeating and not exercising because somewhere deep down in the middle of my being, I know I feel terrible that my siblings have intellectual disability and I don't. I still have to work quite a bit on the concept that 'it's okay that I'm okay'.

It is hard for me to say that my parents 'neglected' me because I don't want to add to their burden, but I know in my heart it is true. I often feel that if I had happy things or positive things to express, that was okay, but if I was negative, that wasn't okay.

I remember in eighth grade I wrote a poem entitled 'My Name is Rachel and I'm Always Happy'. It was about how everyone always thought I was so happy, and told me all their troubles, but I could never tell anyone mine, and I always did everything with a smile, which masked everything.

I felt totally alone at times in my family. My mother protected my brother from the world with a ferociousness that scared me. I was conscious that my father's attempts to nurture me caused conflict between him and Mum. By the time I was 12 I was bulimic; 14, anorexic; 19, clinically depressed. I turned my feelings of anger, hurt, isolation and loneliness upon myself. At 28 I can finally recognise this – it feels like a long road ahead.

I am still struggling with depression. Eighteen months ago I again attempted suicide – it was a terrifying time. What helped me then and now was the support and unconditional acceptance of friends, other siblings and my therapist. They help me feel less alone and less afraid, and they give me strength to deal with my history and consider my future. That sense of not being alone is so important to me.

I realise now that if ever I was mad or hurt or angry (especially at my disabled sib), my parents and I just didn't know how to deal with it, so we didn't. All that 'emotion stuffing' has taken a big toll, and I have been on anti-depressants, in counselling and group therapy for several years.

An AIFS report from 2008 showed that siblings have higher rates of depression regardless of any caring role they may or may not play. This was reinforced by findings from the Adult Sibling Project and other contact with families by Siblings Australia.

In 2013 Siblings Australia conducted a [Phone-in re sibling support](#) to gauge families' thoughts on the availability of sibling support and what would help.

Siblings Australia

Siblings Australia is the only organisation to focus on siblings of children/adults with disability. Over a period of 16 years, it has developed a national and international reputation for its work with families and providers. It's Director has been asked to present in Italy (3 times), Scotland, England, US and Canada. Her book on siblings has been published in Australia, the UK, and US, and has been translated into Korean.

The organisation has developed a number of resources and services for siblings, parents and providers, including:

- sibling groups for young siblings, forums for adult siblings and provides online support services for adult and teen siblings (the latter in conjunction with a leading sibling support agency in the US). When connecting with peers in a safe environment siblings have shared very openly a wide variety of concerns and have given each other enormous support. They have expressed enormous gratitude for the opportunity to share with others who understand.
- fact sheets for adult siblings as part of its [Adult Sibling Project](#) in 2009. The report highlighted a number of issues that still come up in our connections with adult siblings.
- workshops and online/print resources for parents
- professional development regarding the support of siblings, both here and overseas. Again, feedback has been extremely positive. The *Sibworks* program for young primary school aged siblings, developed by the organisation some years ago, has been used by providers around Australia. The DVD, *Stronger Siblings*, was developed to assist organisations to support parents to support their children who are siblings. It includes discussion notes to be used with a group of parents.

- research regarding a number of issues relevant to siblings. Several reports are available via the [website](#). The 2009 [Scoping Project](#) reinforced the need for more sibling support, more collaboration and more resources/skill development. It also highlighted the lack of evaluation in relation to current programs.
- advocacy for the needs of siblings to be recognised. [Submissions](#) have been provided for a number of situations and [advocacy](#) by other agencies (including the RANZCP and Families Australia) has been supported.

In addition to the above, Siblings Australia also hosts a website, which includes a large amount of information and links to resources. The organisation receives many enquiries (via the website, email, Facebook and phone) from siblings, parents and providers from around the country, asking for information and advice.

Articles in [Youth Studies](#) (2001) and the [AeJAMH](#) (2008) explore the work of Siblings Australia from earlier in its history.

During the last 8 years this work has been carried out through the mainly voluntary efforts of its people (Director and committee of management). Without the capacity to train others in this work, the future is very uncertain. It would be regrettable if the knowledge and expertise developed over many years were lost.

Recommendations

As highlighted at the beginning of this submission, the DP states that the actions under the draft National Priorities 'will need to consider the diverse needs of different groups, and work towards addressing unique risk factors'.

In weighing up the future directions of the next Plan it is important that consideration is also given to problems that might not appear so extreme but nevertheless might be easier to intervene and make a difference. Early intervention with siblings can make a significant difference to family strengths and the longer term safety and wellbeing of the whole family. Whilst 'protecting children is everyone's business', is a worthwhile aspiration, so should it be that 'every child is everyone's business', including those that have not, as yet, been widely recognised as at risk.

Siblings Australia has done considerable work in this area but it cannot continue this on its own and would like to make the following recommendations:

1. The Third Action plan makes a concerted effort to identify vulnerable groups of children which have not been identified thus far and which are not included in government policy.
2. Interest is sought from Coalition members to join a small working party, convened by Siblings Australia, to further explore how siblings might intersect with the Third Action Plan.

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