

Submission to the National Carer Strategy Discussion Paper

Siblings Australia congratulates the government on its development of a National Carer Strategy to shape the long term agenda for carers. It is pleasing that the government will “work closely with carers and carer support organisations to ensure the Strategy responds to carers’ needs and experiences”.

However, Siblings Australia has some concerns about the discussion paper, directions for the future development of a National Carer Strategy and the support approaches to families who care. (Please note that this submission recognises that carer roles extend across a variety of situations, eg spouses caring for spouses, children caring for parents, but this submission focuses specifically on families where a child has a disability across the lifespan. In addition, when this submission refers to ‘disability’ it is referring to any special needs, including developmental delay, disability, chronic illness, mental illness.) This submission explores a number of concerns, responds to the discussion paper and recent reports/reforms relating to carers and families, and makes the following recommendations.

RECOMMENDATIONS

Siblings Australia recommends that the National Carer Strategy:

1. Consider how other government reforms such as the COAG National Disability Agreement, the Productivity Commission Inquiry into a long term care and support scheme for people with a disability, the Mental Health Strategy link not only with the National Carer Strategy but also with the support needs of the whole family, and how Siblings Australia might be able to contribute to this.
2. Improve data collection about siblings and research their different roles and needs.
3. Add another goal ie GOAL 6: *Better whole family support for carers*.
Achieving this goal will result in:
 - Carers have support to maintain all family relationships
 - Carers are able to access sibling support programs/services
 - Carers are able to access community programs that support whole family participation

1. PURPOSE OF NATIONAL CARER STRATEGY

The discussion paper states that the government believes that ‘*carers should have the same opportunities as other Australians to participate in work, community, social and family activities, and live a meaningful life*’. It also acknowledges that ‘*many carers face challenges including lack of recognition, poor health and wellbeing, financial stress, and social exclusion. It can be hard for carers to access services and supports for both themselves and the person they care for*’.

Siblings Australia has concerns about the focus on the ‘carer’ role, rather than the focus being on families. The above challenges are as likely for other members of the family; not just so- called ‘carers’. In addition, other family members may contribute much to the wellbeing of the person with disability; in the case of siblings that may continue over a lifetime. Families should be just that and support should be available to the family. The focus on ‘carers’ can isolate families even further from the community.

2. HOW WILL THE NATIONAL CARER STRATEGY HELP CARERS?

The National Carer Strategy will ‘*support carers in balancing caring with work, social, community and family life*’. Siblings Australia would like to highlight two issues related to this section of the discussion paper.

1. ‘Carer’ vs ‘family’ model

Siblings Australia believes there are some problems with using a 'carer' model rather than a 'family' model. Certainly the 'carer' movement has been able to advocate strongly for more recognition and support for carers, which has been enormously helpful to many families. However, there are some issues with this 'carer' model.

First, it is important to ensure that any model does not overlook other family members, but recognises that all family members contribute in different ways and all need support, regardless of any caring role they may or may not have. With so much emphasis on 'carers', many of these other family members are overlooked by government – they have been left out of national strategies in the past.

Also, many parents and siblings would much prefer not to be known as 'carers' – they want to be parents and siblings, ie family, first. They want to take part in the community just like other families. Of course they need support to do that but they should be able to access childcare, school, family support etc just like other families. Of course such families play a greater caring role but terms such as respite care, special schools, carer support etc all distance them from the general community. Families which include disability face enough stigma, without adding to it by the use of such labels. An online survey carried out by Siblings Australia showed very clearly that siblings want to be brothers and sisters and would prefer to access sibling specific support services rather than 'carer' services. Another important factor is that some of their concerns are not related to a caring role.

Also it is important to consider the impact of a 'carer' model on people with disability themselves. It sets up a power differential and does not consider dignity issues for people with disability. What 16 year old boy wants his 14 year old sister to be known as his 'carer'? The use of this term isolates him further from other young people in the community. We need a 'family support' model that is more inclusive, not more isolating.

2. In order to balance family life, parent 'carers' need help to support the whole family.

In the case of children with disability, many parents highlight their concern for their other children and what impact growing up with a brother or sister with disability will have on their wellbeing. Many have actually said that the sibling(s) have become more of a concern than the child with disability. This concern is not without cause. Siblings can certainly be enriched by their experiences but there is much research that shows they may face significant challenges and can be at risk for developing longer term mental health concerns, whether they play a caring role or not. For example, the Australian Institute for Family Studies (Edwards et al, 2008) found that siblings of children with disability had higher rates of depression than the general population, regardless of their caring role. In addition to the research, Siblings Australia has run workshops for thousands of siblings, parents and providers around Australia and overseas and the overwhelming feedback is that these children can certainly experience a lot of stress, often without the maturity and understanding to manage their varied experiences.

Several inquiries in the past have highlighted the concerns of parents about their children who do not have special needs. Also, Siblings Australia has prepared submissions to a number of national inquiries related to families of people living with disability but still siblings are overlooked, in particular, at policy level and there is still no national co-ordinated approach to sibling support. Several inquiries are discussed below.

If the National Carer Strategy is to truly meet the needs of carers, then provision should be made to assist parent carers to support all of their children and to access support services not only for the child with disability but also for their other children.

3. PREVIOUS REPORTS/SUBMISSIONS

There have been a number of inquiries over the years, looking at the experiences and needs of families and carers. Many of these highlight the needs of whole families; others overlook this important issue. The following section looks at a number of inquiry reports.

a) Listen to Us

The 'Listen to Us' report from the School of Social Work and Social Policy at La Trobe University, Victoria, in 2002, showed that one of the major concerns of parents of children with disability was the effect on their other children and how as parents they could support all their children. This is reinforced by the experience of Siblings Australia through its workshops and multiple queries from parents via email and phone.

b) Who cares...? Report on the inquiry into better support for carers

The discussion paper states that the National Carer Strategy will include what the Australian government agreed to do in its response to the 'Inquiry into better support for carers'. In summary, the report from this inquiry by the Department for Families and Housing, Community Services and Indigenous Affairs, states very clearly that carers want choices – for themselves, the people they care for and for their families. The Inquiry's body of evidence clearly illustrates the profound physical, emotional and financial effects that providing care has on carers and on their families. It reinforces that the stress experienced by the primary carer often extends beyond the primary carer to the whole family, and that counselling services are needed for the whole family. However the report did not go further in terms of developing any response to these needs, especially in relation to siblings.

The report made several recommendations, including that the Australian government should:

- Collect better data ie expand info collected by the ABS to include information on secondary carers
- Develop a community education campaign to promote awareness of the role and needs of carers, and include components to engage 'hidden carers'
- Make locally based peer support carer groups a priority within current community grants programs
- Expand MyTime support groups for parents
- Develop a national strategy to address the training and skills development needs of carers
- Review the adequacy of case management for carers
- Provide family advocacy services which better recognise the role of carers
- Extend eligibility criteria for its Respite for Young Carers at Risk Program
- Expand the National Carers Counselling Program to better meet the demand for counselling services by carers
- Raise awareness among General Practitioners of the high incidence of mental health problems among carers and their families and of the options available for support
- Minister for Social Inclusion nominate carers as an early priority for social inclusion

All of the above need to be considered in relation to siblings or families. Why not a MyTime for siblings? Why not a National Family Counselling Program? In addition, identification as a 'carer' was reported to have resulted in harassment and bullying for some young carers. The report states, 'As reported in the submission (number 701) from Siblings Australia in relation to young sibling carers: Siblings [of children with special needs] can be particularly vulnerable to bullying or teasing. One little girl found that others would not play with her as she had 'disability germs'. It must be noted, however, that this young child is not a young carer – she plays no caring role – but she is a sibling, and siblings experience bullying and teasing, whether they play a caring role or not.

In addition to needing time away from the caring role to maintain a positive level of emotional wellbeing, many carers also identified the need for greater access to psychological support and counselling, both for themselves and for their families.

The report also highlighted the impact on other members of the family, as follows: 'The stress experienced by carers often also extends beyond the primary carer, affecting the whole family including spouses, siblings and other family members. Relationship difficulties between siblings, is a particular area of concern identified by recent research. The need for counselling services to ameliorate the impact of caring on the whole family was raised by many.'

The overall evidence to the Inquiry supports the need for emotional and psychological support for primary carers as well as for other family members, including relationship counselling for spouses, siblings etc. As one carer commented:

'Support for carers must include ongoing counselling & emotional support. The grief is raw with no closure, it is ongoing and affects & divides the whole family & social network.'

There needs to be far greater links with organisations such as Siblings Australia when considering the issue of family support.

In addition, whole families need more support to consider future planning options when primary carers are no longer able to provide care.

Siblings Australia's submission to this inquiry can be viewed at:

<http://www.apf.gov.au/house/committee/fchy/carers/subs/sub701.pdf>

c) Shut Out: The Experience of People with Disabilities and their Families in Australia

Australia was one of the first countries to ratify the United Nations Convention on the Rights of Persons with Disabilities as part of the Australian Government's broader long-term commitment to improving the lives of people with disabilities, their families, friends and carers. The government has since introduced the idea of a National Disability Strategy, which "will be an important mechanism to ensure that the principles underpinning the Convention are incorporated into policies and programs affecting people with disability, their families and carers".

A National Disability Strategy was one of the key recommendations of the 2007 Senate Inquiry into the Commonwealth, State and Territory Disability Agreement (CSTDA). The CSTDA report highlighted the need for a coordinated, high level, strategic policy to address the complexity of needs of people with disability, their families and carers in all aspects of their lives.

In February 2008 the Commonwealth, State and Territory Disability Ministers met in Melbourne and acknowledged the development of the National Disability Strategy as "an historic opportunity for the Commonwealth, States and Territories to work together with the community to ensure the needs of people with disability and their families are addressed through coordinated and comprehensive policy planning - across all government departments and services."

A discussion paper was developed for consultation with the community. The resulting submissions and consultations led to the Shut Out report which was launched by the National People with Disabilities and Carer Council (NPWDACC) to government in 2009.

Siblings Australia contributed a submission to the discussion paper regarding a National Disability Strategy, stressing the importance of considering the whole family. Also a joint submission by all State and Territory Children's Commissioners and Guardians highlighted the importance of considering siblings in their own right and also, separately, as carers.

www.ccypcg.qld.gov.au/.../National-Disability-Strategy-submission.pdf

Unfortunately the Shut Out report, in spite of its reference to families and in spite of submissions that highlighted the impact on the whole family, makes virtually no reference to the contribution by, or the impact on, siblings. It is very focussed on the person with disability and their parents. It is alarming that this is the case, as siblings will have the longest relationship of any with the person living with disability, and potentially will have a major influence on their lifelong wellbeing. The report is not a true reflection of the experience of families.

d) 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*

This report on a major investigation of the impact of caring showed that parent carers of children with a disability have higher rates of depression and that other children in the family also have higher rates of depression, whether they provide a caring role or not.

Jenny Macklin, the Minister for Families and Housing, Community Services and Indigenous Affairs, at the Communities in Control conference June 2008 highlighted the needs of siblings of children with disabilities referred to the AIFS report. She said the following:

The research tells us; 1) That carers worry about the impact on other family members, particularly the brothers and sisters of a child with a disability; and 2) That apart from carers themselves having significantly higher rates of mental health problems, their partners and children also experience high levels of depression.

Again, it is disturbing that given this acknowledgement there is no attention given to siblings and their lifelong contributions and needs by government.

e) Muir, K. (2008), Family resilience where families have a child (0-8 years) with a disability: literature review, *SPRC Report 9/08*, report prepared for the Disability Policy and Research Working Group (DPRWG), Commonwealth State/Territory Disability Agreement Australian Government, Social Policy Research Centre, UNSW, February 2007.

This report highlights the importance of understanding “the stressful circumstances some families who have a child with a disability can experience. A child with a disability may require more parental assistance and supervision within and outside the home, than a child who does not have a disability Families with children with challenging behaviours may experience compounded levels of stress.”

It goes on to discuss the extra demands of parenting a child with a disability and how this can affect their working, social and home lives and their family income, through extra costs related to the disability and reduced opportunity to work for mothers in particular. It also discusses social isolation and how this isolation leads to more stress. The needs of other family members may not be met and this can impact on family resilience. While there has been little research on sibling resilience, it is clear that many siblings are at risk for emotional, behavioural and social problems.

The report then discusses the key protective factors for family resilience where a family has a child (0-8years) with a disability, for example, family problem solving and balanced relationships. Where families have young children it is especially important to have “balanced interrelationships among family members” so that the needs of all family members, including siblings, are met and the family can “resolve conflicts and reduce chronic strain”.

It says that key protective factors include parenting programs to support family relationships and specific resources/supports/programs for siblings. Also it suggests that families be assisted to access and understand information and share it with other family members (including siblings) and to provide information/resources that are age appropriate for siblings.

The report stresses that family resilience is based on the family as a group, along with how individual family members perceive situations and how they behave. Therefore family resilience needs to be measured across the family as a group, rather than assessing a single family member. This is practically and statistically difficult because the primary carer will most likely be the family member available for assessment with a practitioner, and, even if other family members (such as a secondary carer and siblings) are available for an assessment, then weighting the family’s responses to elicit a single measure of the family’s resilience is complex.

Again, this research has been overlooked by government.

4. SIBLINGS AUSTRALIA

Siblings Australia has been in operation for over 11 years and in that time has developed a national and international reputation for its work with families and with professionals. It receives many enquiries from

parents about what they can do to support their children who are siblings.

The organisation has worked in a number of ways to develop services, resources and also to promote the needs of siblings. The message overwhelmingly is that parents are concerned about the impact on siblings and they need help to support all of their children. One parent said at a workshop on supporting siblings that she had 'been looking for something like this for 10 years'.

Certainly some siblings may develop very positive qualities through their experiences but many also face many challenges both within their family and in the wider community. Some also experience physical and/or emotional abuse from the child with disability. This is not easy for families to discuss.

Several Siblings Australia reports highlight the needs of siblings and the need for further national strategic directions in sibling support.

Adult Sibling Project

This project involved a number of consultations and an online survey of adult siblings. Adult siblings talked of needing support as children but receiving none. Many expressed love and caring toward their brother or sister with disability, but they also talked about how, in adulthood, they still faced challenges related to their family situation. Many were using quite unhealthy coping mechanisms. Many also expressed concern about the future and what roles they would want or be expected to play. They identified a need for support related to a number of concerns. They preferred to access support via sibling support services rather than carer services, but acknowledged that there was little, if any, out there. There is much discussion around the issue of 'ageing carers' but no consultation with Siblings Australia or individual siblings about their needs and wishes.

Many adult siblings move away from the family, eg they move interstate. There needs to be more research done on why this is so, but from anecdotal evidence it would seem that there may be two main reasons for this. One is that siblings have not had support themselves and may struggle in adulthood with a range of mental health issues, and need to distance themselves from family issues. Also, many siblings become concerned that they may be left with the responsibility of full-time caring if anything happens to ageing parents.

This 'moving away' is a tragedy for the whole family. All family members are missing out on valuable relationships and, as a result, broader social networks. This means that many, often single, parents and the person with disability become even more isolated. If we were to provide support to siblings, over a lifetime, the outcomes would likely be much different.

Many siblings want to be involved in the life of the person with disability – but as brothers and sisters, not as 'carers'. They need support to juggle their own needs with that of their brother or sister as they age. Siblings Australia prepared a submission to the inquiry into options for people ageing with a disability and their families, highlighting the lack of consideration of siblings in the whole discussion.

http://www.aph.gov.au/senate/committee/clac_ctte/planning_options_people_ageing_with_disability/submissions/sub12.pdf

Scoping Project

The Siblings Australia Scoping Project completed in 2009 showed that there were a lot of young sibling programs being conducted around Australia, mainly due to the dedication of individuals who saw the need for such support. The Project found that these efforts were uncoordinated and lacked effective evaluation. Siblings Australia has been concerned for some time about the lack of best practice guidelines but has lacked the resources to develop such work. The Project also showed that organisations needed greater access to workforce skill development. Again, Siblings Australia has run many workshops for providers, and developed resources for different sectors (disability, education, GPs) but there needs to be a greater co-ordinated and collaborative response. The organisation has developed a model for peer support, SibworkS, which is used by many providers with extremely positive results, but again there

has been no formal evaluation. Certainly many siblings feel more empowered after attending such programs and also, according to parents, interact more with their brother or sister with disability.

Reports from both of these projects can be found on the Siblings Australia website:
http://www.siblingsaustralia.org.au/ps_cprojects.asp

5. HOW DOES THE NATIONAL CARER STRATEGY FIT WITH OTHER GOVERNMENT REFORMS?

The discussion paper lists a number of other government reforms and discusses how they fit with this Carer Strategy. This submission responds to these.

a) COAG National Disability Agreement

This agreement states that State governments are responsible for the support of people with disabilities, their families and carers. The reality is far from this. Siblings Australia has been told by a State government official that this agreement is 'purely aspirational' in respect to any support for siblings. Again there is a lot of rhetoric about 'family support'. Siblings Australia receives many enquiries from around Australia from parents and providers but the organisation's resources are limited.

b) Productivity Commission inquiry into a long term care and support scheme for people with a disability.

Siblings Australia provided a submission to this inquiry which stressed the importance of considering the whole family when thinking of people living with disability, from diagnosis and over a lifetime. It stresses the importance of Case Managers to co-ordinate the needs of the whole family.

http://www.siblingsaustralia.org.au/documents/40406.4831944444_Productivity%20Commission%20Inquiry%20Submission%20150810.pdf

c) MyTime – this program of peer support programs for parents of children with disability has been provided with nearly \$20 million in recent years. This acknowledges the need for parents to share with other parents and gain support. However, it is unfortunate that there is not similar recognition by government of the need for siblings to gain such support.

d) Young carers – millions of dollars (some previously and \$25 million over the next three years) It is commendable that governments are considering the needs of young people who provide care. But 'young carer' programs are still missing a huge cohort of young people who grow up in families with a child with disability. Many siblings do not provide any care to a brother or sister with disability, but many of these are still at risk for a range of mental health problems, due to a number of factors both within the family and outside the family. If siblings do provide care, there are many reasons why they should not grow up with the label of 'young carer'.

e) National Mental Health Strategy

When considering mental health and siblings there are two main aspects.

First, the National Mental Health Strategy acknowledges that carers 'provide a vital role in the prevention, early intervention, treatment and recovery for people with mental illness'. This group may include siblings. However, if they do provide care, siblings may not identify as carers nor do they, or their brother or sister with mental illness, necessarily want them to. They need to be recognised for whatever their contribution is to the wellbeing of their brother or sister.

Second, siblings are at risk themselves for mental health problems due to their experiences growing up with a brother or sister with disability or illness. They should be considered in any mental health strategies.

Many national mental health strategies have a focus on promotion, prevention and early intervention and a spectrum of services for high risk families. But they often overlook the needs of families with disability. For example, even though siblings have been shown to have higher rates of depression, there is no government support for a national strategy for siblings.

In November 2009 the government's National Advisory Council on Mental Health prepared a discussion paper to provide vision and suggestions for a co-ordinated response to Australia's mental health needs. The paper would also contribute to mental health reform directions under the *National Mental Health Policy* and the *Fourth National Mental Health Plan* and assist the Australian Government to determine its implementation priorities from the Fourth Plan.

The discussion paper highlighted the need to invest in our children, youth and families, and identified the following as program priorities.

- Acting early and nurturing a healthy start in children and families
- Early childhood, family mental health and developmental services (0-25yrs)
- Schools as hubs for acting early and for supporting children and families
- Increased focus on promotion, prevention and early intervention
- A spectrum of services for high risk families
- Stable housing as a priority

In addition, the Discussion Paper highlights the following as having the greatest potential impact:

- Early childhood and family mental health and developmental services
- Schools as hubs for acting early and nurturing children and families
- A spectrum of services for families at high risk

However, there are some gaps in this discussion paper. It does not include families that include a child with disability or chronic illness in its list of families at risk.

There is much research to show that these families are at increased rate of marriage breakdown, parental depression as well as depression in the other children who are not affected by disability (siblings). Often these siblings need to cope with parental separation, the depression of an often single parent, AND the demands of a child with disability, with impacts in the home and also in the community (eg prejudice, bullying).

The following article refers to the possible mental health issues for siblings and what is needed to support them.

<http://pandora.nla.gov.au/pan/107363/20091002-1309/auseinet.com/journal/vol7iss2/strohmeditorial.pdf>

Siblings Australia has done much to support these families through workshops and online/printed resources. It has also done some preliminary work with the education sector. In spite of a growing national and international reputation for this work, Siblings Australia cannot access support from the Federal government. Both DOHA and FAHCSIA have 'other priorities'. The lack of action on this issue will result in much higher costs to government and the community in future years than any investment now.

f) National Strategy for Young Australians

This strategy includes a focus on improving health and wellbeing and supporting young people in their families including young carers and those who are the children of carers. However there is no specific support for siblings through this Strategy.

6. GAPS

The National Carer Strategy discussion paper has a number of gaps. The focus is very much on the carer role rather than families as a whole and the complexity of family needs. The paper overlooks completely the need of parents/carers for help to support their whole family. It overlooks the contribution of siblings and their need for support, regardless of any caring role. This would not be an issue if siblings were catered for through other government policy or strategies. But they are not included anywhere.

If the government is genuinely concerned about carers, they must provide services to enable parents to feel empowered to support all their children and to access relevant services for the whole family. A proposal for a National Action Plan for Siblings, developed in conjunction with Families Australia in 2010, can be found at <http://www.familiesaustralia.org.au/publications/pubs/siblingsselection2010.pdf>

While it is commendable to be focussing on 'carers', it is our belief that support should be targeted to families, not just the person with disability, not just parents or carers, but to the whole family as it is the whole family that is affected and contributes to the wellbeing of the person with disability. Siblings may

not play any caring role, per se, but still be impacted in a variety of ways through growing up with a brother or sister with special needs.

Over the years there has been much rhetoric about supporting 'families' when in fact the focus is on parents (most often mothers) and the child with disability. The 'Shut out' report highlighted this.

7. RECOMMENDATIONS

Siblings Australia recommends that the National Carer Strategy:

- 1) Consider how other government reforms such as the COAG National Disability Agreement, the Productivity Commission Inquiry and other government programs such as MyTime, Young Carers, link not only with the National Carer Strategy but also with the support needs of the WHOLE family, and how Siblings Australia may be able to contribute to this.
- 2) Improve data collection about siblings and research their different roles and needs
- 3) Add another goal ie *Goal 6: Better whole family support for carers*. Achieving this goal will result in:
 - Carers have support to maintain all family relationships
 - Carers are able to link into sibling support programs/services
 - Carers are able to access community programs that support whole family participation

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