

Adult Sibling Project Email Update Dec 08

This document provides an update on the Siblings Australia Adult Sibling Project, (funded through a grant from the Julia Farr MS McLeod Foundation), to develop resources and services for adult siblings of people living with disabilities.

The main stages of the project have been:

- Developing a reference group with a mix of people representing providers, adult siblings and people living with disability.
- Running focus sessions around Adelaide for adult siblings (including promoting the project and focus sessions)
- Reviewing current literature on the experiences and needs of adult siblings.

The focus sessions aimed to have input from adult siblings about what their needs are now and into the future. Unfortunately we did not have a big response to our focus sessions (five in Adelaide) but we were able still to take some important themes from the sessions. More on that later, but first we feel there might be a number of reasons why the response was low.

- There is no easy way to access siblings – there are no databases available with that information
- Many of the 500 brochures we had printed went to parents and maybe they were not passed onto siblings
- Siblings do not feel they need support
- Siblings feel uncomfortable about asking for support or uncomfortable coming and speaking in a group
- Siblings feel disloyal about talking about their issues and need for support
- Adult siblings not identifying themselves as being part of a group which might have needs as they are more focussed on helping the person living with disability

We do not feel that the response reflects the high level of need in the community.

We would like to extend a thank you to the siblings who came to the focus sessions and shared their experiences with us. Talking with these siblings re-inforced several themes we have found in other research that Siblings Australia and others have undertaken such as;

- Siblings have a variety of lived experiences
- Siblings often feel they don't deserve support – they have grown up with someone whose needs have always taken, and still do take, priority
- Siblings don't feel ok about asking for services for themselves – they are not a 'squeaky wheel' and so are not a priority in government policy and services
- Siblings feel that service providers/government agencies do not give them due acknowledgement and / or respect both in terms of their own needs and what they contribute to the quality of life of the person living with disability
- Siblings find it difficult to convince parents that the future of the person living with disability needs to be planned for and would like resources to help them to do this
- Siblings expressed a need for practical information and support related to their current involvement with, and future planning for, their brother or sister such as information about accommodation services, financial & legal issues, ideas for recreation for or with their brother or sister
- Siblings also expressed a need for emotional support – ideally from other siblings who are dealing with similar issues
- Siblings who are in contact with their brother or sister living with disability identified a number of barriers which make maintaining this contact more difficult, such as demands on their own time as people who have families of their own and are working, conflict with

service providers, lack of respect for the sibling role, and inflexibility of service provider policies and issues around access for people with physical impairments.

One sibling coined the term “silent army”, which we feel aptly describes the lives of many siblings. Siblings contribute both emotionally and in practical ways to the quality of life of the person living with disability without recognition for their contribution from service providers or support from governments for their own needs.

We would like to further explore the experiences of siblings whose relationships with the person living with disability have broken down, in order to explore some of the barriers to these relationships. If anyone can help us with that we would appreciate it. Our sense is that relationships can become strained when siblings are not able to access support for themselves and the relationship becomes too difficult for them. But that is still fairly simplistic and we would really appreciate any other feedback.

The next phases of the project will include:

- input from people living with disability and parents about the barriers to maintaining positive relationships and what might have helped to nurture these sibling relationships
- developing draft resources such as brochures, information packs or web based information which might cover issues such as emotional and practical needs of siblings, how to talk with parents about future planning, what future planning involves, or information for service providers on how to nurture sibling relationships

We welcome your comments about any aspect of this project and these will be kept anonymous. We also welcome any suggestions on how we might have greater access to families regarding the project. A background paper for the project, as well as previous updates, can be found on the website at http://www.siblingsaustralia.org.au/ps_cprojects.asp

If you would like to be on our email distribution group for the project please contact one of us as below.

We look forward to hearing from you

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NEW Siblings Australia Facebook page!!! at
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