

Adult siblings

Within Australia's ageing population it is adult siblings who represent the next generation of support people and/or advocates for people living with disability. Many siblings tell us they have a big commitment to their brother or sister. However, they often lack information about disability services and how to access support for their brother or sister and for themselves.

Disability Services should consider how to support families to plan for the transition of responsibilities and supports from ageing parents to adult siblings where adult siblings are willing and able to take this on. Responsibilities and supports could include financial, residential, emotional, leisure, practical or advocacy matters.

It is equally important, however, for governments and providers not to assume that siblings will take over the main carer role with a person living with disability. In most cases, siblings want to play the role of a supportive brother or sister, NOT a carer. People living with disability often prefer this too.

Siblings need support to create a 'good life' for their brother or sister AND for themselves.

SERVICE PROVIDERS CAN SHOW SUPPORT FOR ADULT SIBLINGS by acknowledging:

- The importance of the support, care and companionship that many adult siblings provide to their brothers or sisters. *I'd like recognition of the sibling role.*
- The varying roles that adult siblings play in the lives of their brothers or sisters. Ideally there should be choice in the roles undertaken by a sibling and an acknowledgement that circumstances may change over time.
- Not all siblings will be willing or able to accept high levels of commitment.
- Siblings should not be expected to 'take over' from parents.
- All sibling pairs have unique relationships which reflect levels of closeness in the family of origin, personality traits, cultural issues and personal resources.
- Some siblings might have left over impacts (sometimes trauma) from childhood experiences which might influence how they now interact with a brother or sister.
- Adult siblings can be 'holders of information' who have a unique view of their brother or sister. *I interact differently from my parents, who often accept anything that is offered to them.*
- Adult siblings can be powerful advocates for people living with disability.
- Service providers have a role to play in assisting people living with disability to maintain relationships with family members (if that is what they want).
- Like parents, adult siblings need support.
...our feelings matter too, we need to be informed, supported and most of all listened to.

WHAT ELSE CAN SERVICE PROVIDERS DO?

Service providers can use the following strategies to help increase awareness and knowledge of the value and needs of adult siblings.

- Develop organisational policies that acknowledge the importance of the whole family.
- Provide training to staff about the experiences and needs of adult siblings as well as the importance of the role they can play in the life of their brother or sister.
- Collect and keep information about sibling contacts on file and in data bases.
- Review the involvement of adult siblings with their brother or sister living with disability at annual planning meetings.
- Talk with parents about including the names of adult siblings as support/contact people.
- Specifically mention siblings in service delivery information.
- Refer to 'family members' rather than 'parents' where appropriate.
- Personally invite siblings to social events or planning meetings rather than always relying on parents to pass on the information.
- Develop programs to help maintain the sibling bond. For siblings who live far way, there are a number of creative ways to do this, such as email, photos and skype.
- Ask siblings if they have information they would like to contribute to 'Personal Profiles' or 'Life Journals' for their brother or sister. They often have a unique perspective.
- Encourage adult siblings to ask questions about the services provided for their brother or sister.
- Where appropriate, encourage adult siblings to be involved in consultation groups, boards of management, etc.
- Understand that adult siblings may continue to experience a range of feelings related to their childhood experiences such as feelings of grief, guilt, pride, embarrassment or confusion.
- Encourage parents to be aware of the importance of planning for the future – for themselves, for their child living with disability, and for the whole family.
- Develop resources and links with local services that can help families plan for the future.
- Refer siblings to the online and face to face opportunities to network with other siblings via Siblings Australia.
- Download this pdf and share with other providers who work with people with disability and their families.