

infolink

Free



Inside

Featuring carers

SA Disability Register invitation

Fathers involved in Signposts

Caring and young people

Yoga for children

Multicultural carers

... and much more

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**Government
of South Australia**

Department for Communities
and Social Inclusion

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Chief Executive,
Department for Communities
and Social Inclusion,
Joslene Mazel

infoLink is for people with disability, and their carers and families. The magazine will also interest those providing services to people with disability.

infoLink is designed to be informative and useful. The magazine focuses on practical help, news and articles that will keep you up-to-date about initiatives, programs and services.

infoLink is published twice yearly. This edition focuses on non-paid carers—the families, friends and neighbours who devote much time and effort on behalf of others. The next edition will focus on people with disability participating in the community.

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Message from the Minister

As the new Minister for Disabilities, I am pleased to note that this edition of *infoLink* coincides with an exciting period of change as we start examining disability service system reform.

I welcome the release of the thorough and well-considered 'Strong Voices' Disability Blueprint report. I recognise that people with disability and their carers have high expectations arising from the report. Be assured that the government is preparing its response to 'Strong Voices' and will be making announcements in the very near future. This report is significant and we need to ensure our response is the right one.

South Australia is also committed to working towards a National Disability Insurance Scheme (NDIS). The NDIS offers us a huge opportunity as a nation to ensure that people with disability and their families have certainty and choice about the support they can expect over their lifetime. We will be making sure that any new scheme provides the best possible arrangements for South Australians and we are keen for South Australia to be part of testing the new system as early as possible. This involvement will ensure your experiences and insights

shape our disability system for the better.

In this *infoLink*, we celebrate the contribution that carers make to the community and write about the challenges, barriers and rewards that the role encompasses.

I trust that the articles gathered here will go some way towards supporting carers and providing access to information, and will promote greater recognition of the positive difference that carers make. More than 250 000 South Australians make a daily important contribution to the South Australian community as unpaid carers.

The State Government is committed to ensuring that South Australian carers continue to get the support and recognition they deserve. The 2011–12 State Budget has a strong focus on health, disability, and some of our most vulnerable families and communities. It provides extra spending of \$37.5 million over the next four years to meet the needs of South Australians living with disability and their carers. This support will assist with accommodation, community access and much-needed respite services for carers.

The support complements the Australian Government's long-term commitment to



Minister for Disabilities,
the Hon. Ian Hunter MLC

carers. The launch of the National Carer Strategy in August 2011 included \$60 million in new funding over the next four years for a carer strategy awareness-raising campaign, carer support services and carer payments.

I acknowledge and thank all those people who freely devote large parts of their own lives to the support of others—not as part of a job, but voluntarily and often in addition to working themselves. You provide help and support in ways that otherwise might not be available. By your effort, patience, knowledge and compassion, you very often transform the lives of the people you are supporting.

A handwritten signature in black ink, appearing to read 'Ian Hunter'. The signature is stylized and cursive.

Ian Hunter
Minister for Disabilities

Family, friends, neighbours

The lid on the jar of olives is very tightly sealed. A car with hand controls is more than the budget allows right now. The shopping centre is a long way off and too large to manoeuvre around without fatigue. Some foods can't be swallowed without processing. The packet of snail bait has complex instructions for safe use. It's hard to be understood at school. Toilet training is proving a bit of a challenge. Sometimes, people just want to go to the movies or down to the beach.

And who is there opening, driving, shopping, preparing meals, reading, teaching communication skills, being patient about timing, going on outings and more? Family, friends and even neighbours who have stepped up, seen the need and become carers.

We're writing here specifically about people who care for others without payment. Paid support workers fulfil a crucial role that we'll cover in a future edition.

Caregiving is a complex undertaking, often characterised by enduring love or friendship, personal sacrifice from all parties, extraordinary achievements, successes to be celebrated and occasional tears and tantrums—even grief. This edition of *infoLink* looks at some of the issues (health, respite, estate planning, multiculturalism and more) and describes services, events, activities and strategies that are in place or underway to make caring an easier road to travel.

If you need more information or want to join some of the activities, call the numbers provided, visit the web sites listed, or get hold of the books and resources named throughout the magazine. We especially draw your attention to joining the SA Disability Register, described on pages 6 and 7.



Definition of a carer in South Australia

A carer provides ongoing care or assistance to a family member or friend who has a disability, a chronic illness (including mental illness), or a person who is frail.

South Australian Carers Charter

- Carers have choices within their caring role.
- Carers' health and wellbeing is critical to the community.
- Carers play a critical role in maintaining the fabric of society.
- Service providers work in partnership with carers.
- Carers in Aboriginal and Torres Strait Islander communities need specific consideration.
- All children and young people have the right to enjoy life and reach their potential.
- Resources are available to provide timely, appropriate and adequate assistance to carers.

The SA Carers Charter is a schedule of the SA Carers Recognition Act; for the complete detail of the Charter principles, refer to the Act at www.sa.gov.au/carers.



Carers' health and emotional wellbeing

Anyone, anytime ... disability can happen just like that; a baby is born with disability, a teenager suffers an acquired brain injury in a sporting accident, someone has a stroke. And so people become carers in different ways—gradually or suddenly—but the ensuing journey is punctuated by many changes and challenges, not all of them anticipated.

More than 250 000 South Australians actively care for a loved one, a friend or a neighbour. The focus of many families is on caring for their loved one with disability and working to ensure they get needed services. Many families and individuals in a caring role do not see themselves as carers. This lack of identification as a carer often means they are missing out on valuable information and deserved support.

It is not unusual for carers to become both physically and mentally exhausted while caring for others, as they often treat their own needs as low priority. Carer organisations exist across South Australia to support families so that carers can maintain their own health and wellbeing, and form and continue connections to their friends and community.



Looking after yourself

Your own health needs

Research shows that looking after someone with high and/or constant care needs can place great stress on a carer's physical and emotional health. Carers should have regular health checks with their own GPs, making sure that the GP knows about the carer's role. Being a healthy family carer also benefits the person for whom the care is provided.

Time for yourself

It is very difficult to maintain a demanding caring role without taking regular breaks to rejuvenate and focus on other parts of life. It is important that carers are able to maintain

contact with their friends and the broader community. Carer organisations can help carers access services and support to help get time out from the caring role through short or longer respite periods. Many families may feel reluctant to use respite, but it is well-recognised that the break provides benefits both to the carer and to the person needing care.

Talk things over

The caring role can be an isolating experience at different times for many families; it is not unusual to feel alone and unsupported. Carers' emotional wellbeing can be helped by talking things over with others in supportive peer and social networks, or with a professional counsellor. Linking into carer organisations is a great way to make these connections.

Services and support

Caring families do not always have to carry the responsibilities of caring alone. Carers SA is focused on ensuring that identified family carers also have a much-needed range of support services. The range of services around ongoing support for family carers means families can find the best mix for their needs. Linking into local carer support organisations is an essential step

to getting the necessary care and support to which carers are entitled.

Carers, contact us at Carers SA on 8291 5600 or freecall 1800 815 549 to talk about your situation and the assistance that may be there for you. Visit the Carers SA website at www.carers-sa.asn.au. We provide information sessions and courses to give people knowledge and skills around caring.

Carolyn Donaghey

Policy and Project Officer, Carers SA

Telephone 8291 5600

Email info@carers-sa.asn.au

South Australian Disability Register

You are invited to participate in a pilot program to develop a South Australian (SA) Disability Register. We are seeking participation on the disability register from people living with disability and their families, along with individuals and agencies across the community interested in topics concerning disability.

The SA Disability Register is a way to engage with people on specific issues concerning disability for the purpose of recommending to the Minister for Disabilities changes to the way the government does things in relation to disability. The disability register is part of a new way for government to engage the community on disability. This strategy was discussed in an article in the July 2011 edition of *infoLink* magazine. As outlined in the article, a discussion paper (*Consumer Engagement Strategy for Disability*) was circulated for feedback by the former Department for Families and Communities.

Subsequent feedback to this discussion paper endorsed the new way of consulting with the community. The central idea behind this new strategy is that many people in the community have significant levels of experience, knowledge and expertise that could be usefully harnessed to develop positive reform.

Registration to the pilot of the disability register has been running since September 2011 with the aim of a full rollout of the program in early 2012. The initial group of 120 people was invited to participate in the pilot. The aim of this initial phase was to develop and test the new register, including the online infrastructure and supporting information systems such as the database. The second stage of the pilot, to which you are now invited, will run until February 2012 and will include a round of engagement on an agreed topic and feedback on the pilot project as a whole.



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Using the SA Disability Register

When the register is fully operational, members of it will inform specific topics of engagement through the use of surveys, focus groups and online facilities.

It is envisaged that engagement topics will not be confined to just disability services but will be chosen on the basis of the community priorities, and those areas with the best potential for policy review and change.

The method of engaging the community may bear some similarities to the inquiries recently funded by the Commonwealth and South Australian Governments addressing disability funding, citizenship and inclusion.

As you may be aware, 'disability' as an area of discussion over the past year has remained at the heart of community and government concern, due in part to the publicity generated by inquiries that included the Disability Care and Support public inquiry, the study of human rights in Australia and *Strong Voices. A Blueprint to Enrich Life and Claim the Rights of People with Disability in South Australia (2012–2020)*.

The aim of the register is to continue these conversations and inform changes to disability policy to the Minister for Disabilities. The Ministerial Disability Advisory Council (MDAC) may assist further in the development of these policy recommendations.



Participating in the SA Disability Register pilot program

The Disability Register is intended to identify your experience along with your interests and expertise on the topics concerning disability. If you do nominate, your preferred method of participation will be identified through the Disability Register nomination form.

You can register online and download additional information by following the links from <http://consult.dfc.sa.gov.au>.

For any further information, or if you prefer a nomination form to be mailed to you, please telephone Bruce Becker on 8415 4278 or email him at bruce.becker@dfc.sa.gov.au.

A return paid envelope will be enclosed.

Bruce Becker
Community Engagement Officer
Telephone 8415 4278
Email bruce.becker@dfc.sa.gov.au

Signposts: talking with fathers

Signposts for Building Better Behaviour is a program that helps families to understand and manage the difficult behaviour of some children aged 3 to 16 with developmental delay or intellectual disability. Evaluation shows that *Signposts* strategies have been used successfully by families to deal with a wide range of behaviours.

Participants (mainly mothers) in groups run between February and May 2011 reported that a session for fathers would help their families to work better together to use the information from the program and maintain improvements. It was also highlighted that fathers often provide specific and unique contributions to parenting that could be better supported.

Consequently, a *Signposts* session was developed for fathers that reviewed the content of the *Signposts* program to consolidate gains. Ways were discussed of working within the family as a team and dealing with stress. Fathers were provided with an opportunity to share their perspectives, including some of the particular challenges they face and the strengths they bring to their families.

The facilitators were encouraged by the men's openness to discuss both the challenges and rewards of being a father of a child with disability.

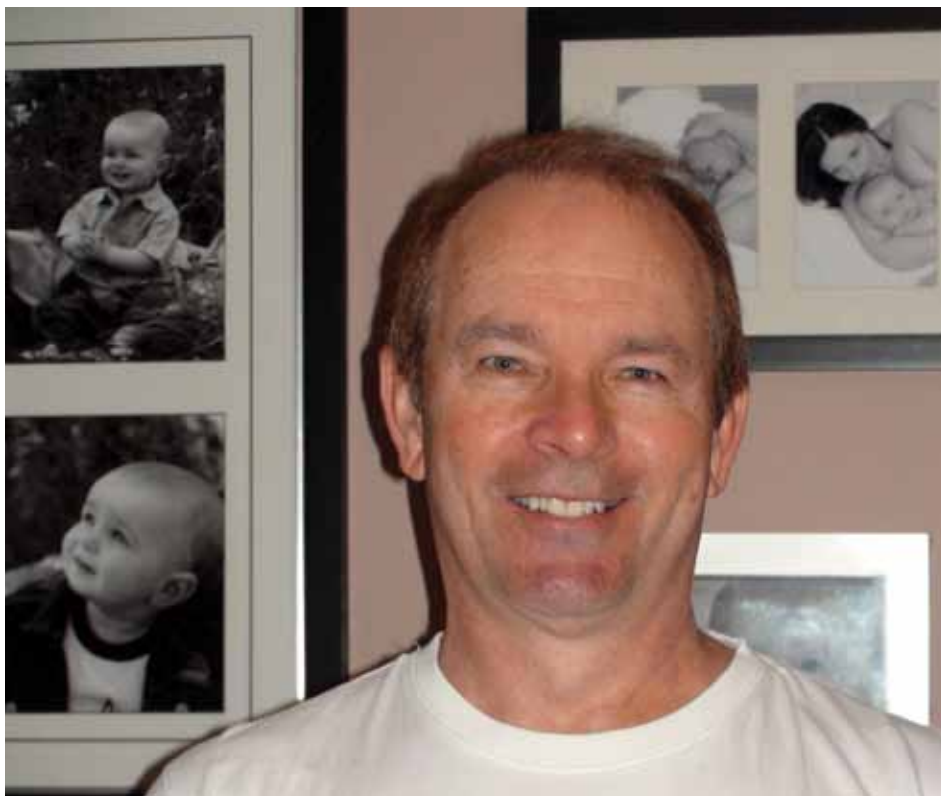
The men expressed their appreciation to their partners for the partner's contribution to caring for the children, the support given to them as fathers and the way their partners kept the family together. The men reported that they had found the session beneficial.

[It was] definitely good to speak with other fathers ... I learned that a lot of fathers are having similar difficulties with family life ... I learned some positive ideas to try from the other fathers.

Bernard, father of Aiden (8-year-old boy with autism)

It was good to get a glimpse of what our partner was learning and implementing these ideas at home with our son [and] understanding our role in supporting them and keeping it consistent to better educate our son on his skills and behaviour. Also it was good to meet all the fathers.

Hung, father of Jaiden (6-year-old boy with autism)



Greg, a Signposts father, in front of photos of his family

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[I learned] the need to rethink previous ways of dealing [with behaviour and] ... the need to develop a strategy and stick to it [The session was] very enlightening The honesty [of fathers] was impressive and the sense of real compassion—very real. I was impressed by the depth of involvement. Carry on with the fantastic job.

Greg, father of Dannon (4-year-old boy with developmental delay) and Grady

It was good to hear the perspective of other fathers ... and to hear the experiences from other cultures.

David, father of Marley (5-year-old boy with developmental delay), Connor (10-year-old boy with autism) and Flynn.

When asked what Disability Services could do to support fathers better, the men expressed appreciation at being able to meet with other fathers around important issues despite having very limited time. As Hung put it '... all I can say is, just be there for us when we need support and listen to what we have to say'. Additionally, David stated that '... fathers need the opportunity to talk to other fathers who are experiencing the same thing and need [opportunities] to relax and release in the same process'.

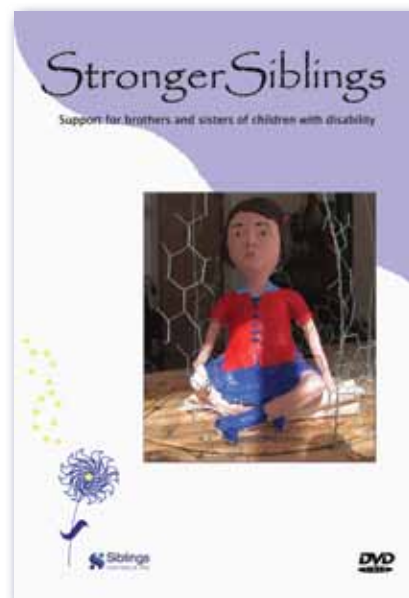
Many men reported difficulties in attending groups because of work commitments; however, some suggestions made provided opportunities for fathers to connect with each other in ways compatible with demands on their time. David suggested having two to three opportunities a year for fathers to meet in sessions that included both information and social components. More men would be able to attend if these events were held at times that suited working fathers, such as Saturday evenings or pre-work breakfasts. It was also suggested that some of these events could cater for both parents, and that busy periods such as Christmas and Easter should be avoided as families are already overcommitted at these times.

Disability Services is keen to support the involvement of fathers in our service. If you would like to share your perspective, or be involved in future programs, please contact your local Disability Services office.

Katya Schiavone, Mark Turner, Kieu Nguyen & Stephen Sheehy
Psychologists, Child and Youth Service, Disability Services
Telephone 8348 6000 or 8366 7300
Email mark.turner@dfc.sa.gov.au

New DVD for parents

A new DVD, *Stronger Siblings*, developed by Siblings Australia and presented by Andrew Daddo, was launched in Adelaide in November 2011.



The DVD will help parents and those working with families to understand the experience of brothers and sisters of a child with disability and how to support those siblings.

Parents and siblings share their stories and, together with professionals, explore issues. It's a resource for organisations to use with groups of parents, especially since the DVD includes notes to facilitate further discussion.



Caring: young people and children

'Caring' is a positive part of our culture through which we support and provide care to those close to us.

Research increasingly reveals, however, that the role of caring has economic, social, health and wellbeing effects on and for individuals across all ages. The effects differ across age groups too; the issues for 50-year-olds providing care for a partner of 35 years will be very different from those where the potential carer is a child of five to 12.



Young people providing care—why they don't seek support

Only in recent decades has caring begun to be recognised. Young carers continue to remain largely unrecognised for a range of reasons including the child and family tending to understate the caring contribution of the young person as 'helping out', as 'what families do' and/or because of concern over what others will think—including child protection agencies.

Many young carers are targets of bullies at school as a result of the perceived 'difference' of their lives and therefore, they will not divulge their circumstances if there is a risk of being disbelieved or not understood.

Research again shows that, although caring can be a reality for any young person because

of their particular family and personal circumstances, it is more likely to be so where there has been migratory activity or disruption has occurred to the family network, or where the family is headed by a sole parent.

The effect on young people providing care

Young people who try to juggle schooling and the range of caring responsibilities typically won't have time to identify services even if they recognise themselves as a young person providing care. They may not have the confidence to approach the service. They may be discouraged by the processes required to access the service and possible waiting lists. They may be discouraged by previous poor outcomes.

Services to young carers are not uniformly available; in many areas, especially rural and remote regions, specific services for young carers may not exist. The result is that young carers or their families may be unaware what support is available and do not seek or receive support until a crisis occurs.

Young carers risk social exclusion from key activities, such as accessing services, connecting and talking with others in a similar situation, and securing a job.

Young people who are providing care are at risk of disadvantage. They are more likely to live in a household that relies on income support and to experience financial vulnerability.

They have a reduced likelihood of completing their education and successfully transitioning to employment. This likelihood is greater for young people from culturally and linguistically diverse (CALD) and indigenous backgrounds, from regional and remote areas, and where the care recipient has mental health issues.

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There is a marked difference in a young carer's ability to participate in employment, especially in relation to full-time work opportunities when compared to all young people.

Australian research on young children and young adults who provide care

An Australian Research Council (ARC) Research Linkage Project is being undertaken through the Social Policy Research Council of the University of New South Wales. The project is led by Professor Bettina Cass, and titled *The Young Carers: Social Policy impacts of the Caring Responsibilities of Young Children and Young Adults*. Some interim findings stated above are derived from this major three-year Australian study, scheduled for release soon. The report findings will contribute to policies for young Australian carers, a national public policy priority. Research outcomes will contribute to evidence about the diverse socioeconomic and demographic characteristics of young carers and care recipients, and to developing supportive policies and services.

Information for young carers in South Australia is available on www.sa.gov.au/carers. A map section has been added to this South Australian Government website that allows carers, including young carers, to enter their postcode to get the details and location of their nearest local carer support service (see page 28).



Carers SA workshop for educators

There are estimated to be nearly 15 000 young people under 18 in South Australia who take on a caring role for a family member with disability, illness, mental health issue, or drug or alcohol problem. One in 10 children and young people have caring responsibilities (and are young carers); that's 2 to 3 students in every classroom.

Many young carers find relationships with teachers increasingly difficult as they struggle to maintain regular and punctual attendance or to keep up with school work while keeping their home situation private. Teachers and school counsellors must be able to recognise the signs that children and young people are fulfilling a caring role at home before they can provide support and understanding.

Carers SA developed the Young Carers in Education Workshop package to help teachers and school counsellors to identify and support young carers in education. The workshop can be tailored to suit primary or secondary school and is delivered as an interactive session of up to 45 minutes. Topics covered include impacts of caring, how young carers may feel at school, and practical strategies and suggestions for teachers and school counsellors to use when helping young carers in education.

Staff attending the workshop receive an information pack containing the Carers SA *Young Carers in Education* booklet, the Carers SA USB stick, and the *Primary and secondary school teachers guide to working with young carers*. Contact Carers SA to arrange a workshop. Visit their website on www.carers-sa.asn.au/how-can-we-help/young-carers.

Office for Carers

Telephone 8207 0454

Email dora.martino@dfc.sa.gov.au

Emma Johnson

Young Carer Worker

Telephone 8291 5600

Email emma.johnson@carers-sa.asn.au

Carers Mediation and Counselling Service

In the UnitingCare Wesley Carers Mediation and Counselling Service (CMACS), we are interested in how we can work with carers and their families around relationship difficulties. We work, too, on untangling the complexities that can arise from unhelpful 'ways of being' that sometimes develop in families because of caring demands. (Families, of course, take many forms, from single parent units to a broad expanse of relatives and connections.)



We support families with counselling and future planning for their family member with disability (including mental illness). Future planning for a family member with disability, or because the carer is ageing, can be difficult. It is an important part of our counselling service and gives carers the opportunity to work through a wide range of issues and concerns.

How can our service help?

The CMACS is located within Family Services at UnitingCare Wesley Adelaide, at 10 Pitt Street and at our Mile End office, where we work with families, individuals, couples, children, and also with men, sometimes around domestic violence.

The CMACS service is a free and ongoing service, and we have an outreach service for people who are unable to come to our offices for counselling.

Mediation is a voluntary process of dispute resolution. Our counsellors are trained in family mediation, and we can help families to find consensual agreement in a respectful and non-judgemental way.

Through our work with carers, we have knowledge and awareness of services that offer support. We offer information and referral to appropriate services.

Carers Support Group

We also facilitate a Carers Support Group at 10 Pitt Street, Adelaide, on every second Wednesday, where carers can come together in a friendly informal atmosphere.

The support group is an opportunity for carers to share stories of courage, resilience and creativity in their roles as carers,

as well as to talk about the tough times. We also share skills and knowledge, support and resources from other carers who have experienced similar situations. We often have a few laughs as well.

Our contact details are:

- Mile End office: 101 Henley Beach Road
Telephone 8150 7213
- Adelaide office: 10 Pitt St, Adelaide
Telephone 8202 5190.

Philip Martin and Mary Ewart

**Counsellors - Family Services, in the
Carers Mediation and Counselling Service**

Email philip.martin@ucwesleyadelaide.org.au

Email mary.ewart@ucwesleyadelaide.org.au

Siblings: the bond that can last a lifetime

The sibling bond can be very strong in any family. Despite ups and downs, joys and stresses, the relationship is often the most enduring of all, providing love and support over a lifetime. The same bond can certainly be true when one sibling has disability. Some siblings say that growing up with a brother or sister with disability 'made me who I am'.

However, there are challenges too. Siblings may struggle with some of their feelings and experiences, but feel they have no-one with whom they can talk. Their reactions to their situation may change over time and will depend in part on the type of disability, the ages of children in the family, how the disability is managed by the whole family and the responses of people outside the family.

Siblings are likely to feel better about themselves when supported from an early age, and when able to understand what is happening around them. Support helps them feel more important in their family, feel stronger, and develop into healthier, happier adults. There has been a tendency in recent times to include siblings under the 'carer' umbrella, but siblings need support, regardless of any caring role they may or may not play. If the whole family is supported from the outset, all its members are more able to identify their strengths and learn to manage any challenges.

Siblings Australia has developed a range of resources and services for siblings, parents and providers. We run a recreational program called 'Saturday Sibs' for young primary school-aged siblings. We have developed resources for a peer support program, 'Sibworks', where siblings can come together, have fun, share experiences and develop skills to manage the challenges. The program, used

by many organisations, has been shown to have a positive impact on siblings and their family relationships.

Siblings Australia also runs workshops for parents on how they can support siblings and for providers on how they can support the whole family. We've also just launched a new DVD for parents (see page 9). The organisation's website has a range of information for families and providers, including schools and GPs.

Siblings Australia has also had a longstanding interest in adult siblings. As mentioned earlier, some siblings remain lovingly involved in their brother's or sister's life. Others find the challenges too much and may have anxiety about the roles they may be expected to play, especially as parents age and become less

able to provide care and support. Siblings Australia heard from siblings around Australia as part of an Adult Sibling Project conducted in 2009–10. It was clear that siblings had a number of varied concerns and highlighted the need for sibling-specific support. A series of fact sheets for adult siblings was developed with the following topics: Sibling Roles, Advocacy, Emotions, Future Planning, Families Talking, Information for Service Providers, and Useful Contacts.

Again, support for siblings helps to strengthen all family relationships. Supported siblings feel better themselves and they are also more likely to contribute significantly to the social and emotional wellbeing of the person with disability over a lifetime.

Get more information and join our mailing list at www.siblingsaustralia.org.au.



Kate Strohm
Director, Siblings Australia
Telephone 0408 720 558
Email kate@siblingsaustralia.org.au

The value of respite

A sister's story epitomises Interchange and what it has aimed to do in its support of children and young people with disability over the past 26 years. In reading Kathryn's recollections, parents can be reassured that having their child in the care of a volunteer host family does not in any way equate with 'not wanting' the child, but rather is a way of enriching that child's life and an opportunity to teach others in the community about celebrating 'difference'. Kathryn's story also illustrates how important it is for siblings to have a 'breathing space'. The Interchange host family program is all about families—one family supporting another in a total win/win situation. Chris Walsh, social worker
Children's Programs, Interchange
Telephone 8132 5300, <http://sa.interchange.org.au>

Kathryn's story

A thesaurus search for the word 'respite' reveals one synonym to be the word 'interval'. Interchange to me—as a then-7-year-old and now as a 21-year-old—provided me and my mother with just that, an interval; a wonderfully timed breathing space. This monthly weekend-long interval was just enough to stretch and go somewhere before we needed to be 'back in the theatre' of our real lives, but also short enough for me to be always waiting for the clock to tick over to 5.00 pm on Sunday when my brother Nick would be home again. It truly was a perfectly timed interval.

We first met Nick's host family when I was 7 and my brother 9. We were invited to their house and walked into an instant welcome; we felt right at home. It was like visiting a favourite aunt and uncle's house as we were treated to a giant Freddo. We played games and watched TV while mum and Nick's host parents chatted over a cuppa. This occasion was momentous, as from this first encounter followed a 14-year friendship that continues to this day.

We must credit Interchange with their host-matching abilities as we could not possibly have been matched with a better family. Even now, as a 23-year-old, Nick lunches with his host family as their relationship continues.



Nick, in red, and his host family

The Interchange weekends have been indescribably valuable to our family. They've benefitted and enriched everyone's lives, not only ours, but also Nick's host family.

These weekend intervals gave me the opportunity to have friends over, to relax, and to have a weekend where we could do whatever we wanted to. We could look at hairclips and earrings and even stand in queues. Most importantly, it gave me time to spend with Mum, just one-on-one. I look back on those days and remember them as 'Mummy and Me' times: times when we could cook and shop and take our time doing it, or go somewhere special. And then we would always go home, eagerly awaiting Nick's return.

For Nick, these weekends gave him friendship, a huge family (most of our relatives were interstate) and, of course, a fantastic weekend. I can see that, through the weekends he spent with his host family, he gained better communication skills and more independence; his host dad even taught Nick to tie his shoe laces! Nick would have a wonderful weekend away and often would have quite the adventure; whether a trip to Victor Harbor or a visit to 'granny's house', he would always have a story of fun to tell.

Interchange has strengthened our family. It has given us support and friendship. It has given us nothing but happiness. And it is not only our family who feels this, as is evident from the families who meet for the annual Interchange family picnic. My endless thanks go to the team at Interchange and to Nick's host family. You have both made such a positive difference to my family's lives.

Massage group allows mums and kids time to bond and relax together

In May 2011, three of us (Jill, Bec and Kelly), working as Disability Services Early Childhood Program physiotherapists, completed training with the International Association of Infant Massage. Infant massage is thought to have many benefits for children and their caregivers. As physios, we were keen to extend the opportunity to benefit from massage to the children with disability with whom we work.



In term two of the 2011 school year, a group of mums and their children gathered at Forbes Children's Centre in South Plympton to learn some simple massage techniques. The children ranged in age from 11 months to 5 years.

The children were star performers, settling back on their pillows on the floor and enjoying the massage strokes. Over several weeks they were able to help their mums learn how to massage legs, stomach, chest, arms, back and face. We all had a giggle while learning the gentle arm and leg movements, especially on the older children, whose mums did an amazing job controlling limbs moving in all directions! The mums were fantastic practising the massage techniques at home when they could. One mum told us ... *[this group] has been invaluable [to] gaining skills I will use at home* and another commented that she ... *gained confidence in massage and encouragement to do massage regularly.*



The relaxed environment allowed for lots of chat and story swapping for mums, and everyone enjoyed coffee and cake at the end. One mum commented that she had enjoyed *a lovely relaxing morning* and another said that ... *[my child] is able to relax and enjoy quiet time with me.*

The children were not to be outdone, demonstrating lovely communication during massage. They made engaging eye contact with their mums and made lots of sounds. One mum told us that her daughter was really 'chatty' when they shared a massage at home. Others commented ... *my child gained longer periods of focus and calm and [gave] more eye contact, and ... it was a nice bonding time with my child.*

A big thank you to all the parents who have joined us for massage group. It's been great to share these massage techniques with you.

The Disability Services physiotherapists hope to run further groups at other locations in 2012.

Speak with your Disability Services Early Childhood physiotherapist if you're interested in coming to a massage group. We welcome mums, dads, grandparents and other carers.



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Yoga for children

Every Thursday afternoon during school term, a group of children with disability aged between 5 and 12 years, come together at the Wandana Community Centre for their weekly yoga class. Organised through Disability Services, the program has been developed by Cate Bales, a yoga instructor who specialises in yoga for children with special needs, and Anne Krishnan, senior occupational therapist from the School Age and Youth Team, Gilles Plains. The class has been running for nearly 12 months.

The classes were initially designed to help teach children with Autism Spectrum Disorders how to manage their anxiety so they could function more productively in stressful situations. The group has expanded to include children with intellectual disability and developmental delay.

The aims of the class are to help children learn to regulate their stress and anxiety; increase their emotional awareness; improve coordination, body awareness, flexibility and strength; and practise socialisation skills in a supported environment.

The children thrive on yoga's positive routines. On entering the class, the children remove their shoes and socks, and choose a yoga mat to sit on. Having their own yoga mat helps to define their boundaries. We always begin with a deep breathing practice such as 'balloon belly breathing', which is a self-calming practice. This start is followed by twice repeating 'magic words' (positive self-talk). The routine is exceptionally powerful and the children are encouraged to use their breathing and magic words independently, to help them get through life's difficult moments.

Yoga builds self-awareness. Through the regular practice of asanas (yoga poses), the connection between the brain and the body is improved. These poses help strengthen postural muscles and increase flexibility and balance. By becoming more connected to themselves, the children learn to connect to other children. Many friendships and connections have been created as a result of our weekly yoga class.

The children learn to recognise the signs of anger, sadness, frustration and grumpiness, and by using their yoga toolbox, they can remain

calm and steady. Feedback from both the parents and children has been positive with the children looking forward to their yoga class each week. Sharon, mother of 8-year-old Holly-Anne who has Asperger syndrome, says the yoga classes have helped '... teach valuable relaxation skills to Holly-Anne that she will need to use throughout her life. It's given her improved strength and muscle tone and helped with socialising'. Parents also have enjoyed catching up together each week

while the class runs and providing an informal support network to each other.

The Yoga for Kids with Special Needs runs in school term on Thursdays from 4.00 to 4.45 pm at Wandana Community Centre, Gilles Plains. Contact Anne Krishnan at Disability Services on 8366 7300 for information or email Cate Bales, Seeds of Growth at cbales@aapt.net.au.



When I feel like bursting or exploding, I practise 'volcano' to let off steam in a positive way. When I feel anxious and worried, I practise 'reach for the sun' to empower me. Yoga participant

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The Tri State Games: sport and socialising

The yearly Tri State Games encourage active participation in sport, provide development and social interaction opportunities, and culminate in a formal gala dinner.

The positive effect on the athletes' personal, social and sporting lives is enormous, extending throughout the year beyond Games week. Travelling, networking, attending training camps, joining in decision-making and team meetings, fundraising, learning new skills and being physically active are opportunities to which all members of the Games community aspire.

Of course, it is sport that the Tri State Games encourages most; one measure of success is the increase each year in the number of people with disability who become involved. Athletes are able to compete in a variety of team sports, athletic track and field, swimming and indoor sports throughout Games week.

A local athlete whose family sees the yearly benefits of the Games is Nigel Freer. Sharon Freer, his mother, tells the story here.

Nigel is a member of the Triangle Trekkers team from Yorke Peninsula, who has competed since the 2004 Echuca-Moana Games. I accompanied the Trekkers for the first time in 2005, continuing since as a volunteer and proud supporter of the Trekkers and the Games.

At my first Games, the immense range of emotions, challenges and experiences I witnessed and felt endorsed the positive outcomes for all involved in the Tri State Games. The opening day was amazing—to see the enthusiasm of the athletes as they reunited with those they'd met from the year before was inspirational, with eager faces, hugs and handshakes. I loved their team colours, the effort they'd put into their banners and parading in their teams through the streets, cheered on by the townspeople.



The evening events at the Games are joyful occasions too, with medal presentations and entertainment. At the first bars of music, there's a surge of people to the dance floor and inhibitions go out the window! The theme nights are great fun with costumes suiting all budgets and levels of creativity.

I remember the first medal presentation I attended: I didn't know how medal winners are determined. As Nigel hadn't 'won' any of his events that day, I didn't expect to hear his name called. But it was, and he was very excited. It was very emotional watching him receive his medal—there wasn't a dry eye at our table!

Nigel lives in supported accommodation, so the Tri State Games are a valued shared experience for him and his family. His sister, Renee Oster, volunteered at the Mildura and Grampians Games, and Nigel's father Peter assisted the team in 2010. Special moments last year were the track events where two father-son teams competed against each other—Peter verbally assisting Nigel (pictured above right), and Neil verbally assisting son Malcolm of the Marion Allstars (pictured above left). Nigel's extended family and friends also readily support him and his team's fundraising.

Learn more about the Tri State Games by calling Sean Hames on 0401 217 517 or visiting the website at www.tristategames.com.au.

Many resources to plan ahead and stay safe

Every year, thousands of Australians are caught up in heatwaves, floods, bushfires and other extreme events. Planning ahead is the key to staying safe in these situations.

As some people have said, 'The time to repair the roof is when the sun is shining'; having an emergency plan on which you're ready to act can make all the difference when the storm clouds gather.

Emergency plans

The former Department for Families and Communities produced the *Keeping Safe in Emergencies* guide, a flip-chart that provides easy access to information on things you can do to be better prepared and safer in specific emergencies.

Keeping Safe in Emergencies doesn't replace detailed plans you may have for specific emergencies (for example, a *Bushfire Survival Plan* or a *Flood Safe Plan*) but it is a valuable resource for any household. Get more information at www.dfc.sa.gov.au/pub/tabId/269/itemId/3333/Keeping-Safe-in-Emergencies.aspx or by calling 8415 4184.

The Red Cross has wide-ranging information on emergency planning and emergency kits. There are large print, disability-specific and audio versions available. Get more information at www.redcross.org.au/ourservices_acrossaustralia_emergencyservices_resources.htm#fact_sheets or by calling 8100 4500.

The Federal Government has produced six *Community Safety Action Guides* (see 'Heatwave' example next page) for culturally and linguistically diverse communities, or people who prefer picture-based information. Get more information at

www.em.gov.au/Emergencymanagement/communityengagement/Pages/Communitysafetyactionguides.aspx.



Bushfire and fire safety

The SA Country Fire Service (CFS) has excellent resources on bushfire safety, bushfire survival plans and Community Fire Safe groups.

The CFS launched a new smartphone application in October. The free app

provides users with bushfire alerts and safety information at their fingertips, wherever they are in South Australia, including:

- current fire ban information and Fire Danger Rating information
- what to do and what not to do on days of high fire danger and fire ban
- information on Bushfire Safer Places near you
- 'email friends' function to keep them informed of your intentions in the event of a bushfire
- *How Bushfire Ready are you* checklist and more.

Visit www.cfs.sa.gov.au/site/bushfire/home.jsp or call the CFS Bushfire Information Hotline on 1300 362 361. However, always call 000 for emergency help.

Information on preventing and escaping house fires can be found at SA Metropolitan Fire Service's (MFS) website at www.mfs.sa.gov.au/site/home.jsp or obtained by calling 1300 737 637. Again, always call 000 in an emergency.

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Flood safety

The FloodSafe program run by the State Emergency Service (SES) has its staff visiting residents, businesses and schools in flood-prone areas to talk about self-help strategies and ways to reduce flood damage. Call 8463 7931 or 0407 794 756 to learn more about FloodSafe presentations. The SES has flood plans online for households.

Get more information from www.ses.sa.gov.au/site/community_safety/floodsafe/emergency_floodsafe_plan.jsp or call 8463 4171. Call 132 500 in an emergency.

The Red Cross booklet *Cleaning up after Flooding* will be of value if your house has been flooded. Download it from [www.redcross.org.au/files/Cleaning_up_after_flooding_booklet\(2\).pdf](http://www.redcross.org.au/files/Cleaning_up_after_flooding_booklet(2).pdf) or get a copy by calling 8100 4500.

Heatwave safety

The SES *Heatwave Information Guide* has many helpful tips on reducing the effect of extreme heat and responding to heat stress. Download the guide at www.ses.sa.gov.au/public/download.jsp?id=5296 or obtain a copy by calling 8463 4171.

Symptoms of heat stress include headaches, lethargy, nausea and vomiting. More severe symptoms can include weakness, confusion and, in extreme cases, collapse, loss of urine output and a cessation to sweating.

Contact your local GP or phone *healthdirect Australia* on 1800 022 222 if you're feeling unwell during a heat wave. Always call 000 for emergency help.

A fact sheet—*Preventing heat-related illness*—is on SA Health's website at www.sahealth.sa.gov.au; search for 'heat related'.

Storm safety

There are many actions you can take to reduce the risk of damage from storms.

The SES StormSafe program has a list of important preparations on their site at www.ses.sa.gov.au/site/community_safety/stormsafe/before_the_storm_hits.jsp. You can call 8463 4171 if you prefer. Call 132 500 for help in a storm emergency.

Earthquake safety

Parts of South Australia, including Adelaide and the mid-North, have a high earthquake potential. Having a plan for the time after an earthquake can reduce its harmful effects.

Visit www.ses.sa.gov.au/site/community_safety/earthquake_information.jsp or call 8463 4171. Call 132 500 for emergency help.



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Future planning: more than just a will



Estate planning is more than just preparing a valid will. It's making sure that provisions have been made for your family and that your assets go where you want after you die. Planning your estate is an important part of an overall financial plan, and should be prepared without delay for the sake of families.

Working out what you need

Have you considered whether you have sufficient assets accumulated to provide for your family and pay off any debts in the event of your death? What if you're injured and unable to control your investments? Have you chosen someone to manage your affairs while you're recuperating?

You may already have a simple will that leaves your assets to various people. Bear in mind that this will may not be the best option for your particular circumstances, especially if you have children from a previous marriage or your own relationships have changed.

When looking at your estate planning needs, you should consider who you would like to inherit your assets, which assets they'll inherit and in what proportions. Your estate planning needs and objectives should be reviewed on a regular basis, and particularly when an important event occurs. This event might be a marriage or divorce, a change of employment or retirement, the birth of a child or death of a relative for whom you've provided.

Your child with disability

Parents of a child with disability are usually very concerned about what will happen to an adult child once his/her parents are deceased or too old to care for them. Who will provide for them? Where will they be accommodated?

There may be concerns about who will provide materially for your

child after your death.

Although your child will be eligible for a disability pension, it may not be sufficient to provide the additional services, clothes, entertainment or accommodation to which he or she has been used, and which add to the enjoyment of life.

You can establish a special disability trust. Centrelink allows parents to set aside money to provide care and accommodation for a family member with disability. That money is not then taken into account when Centrelink assesses the eligibility of you or the child to obtain benefits.

You can also make provisions in your will for money to be set aside on your death and held in trust to provide money for the care, management and maintenance of your dependent family member during his or her lifetime. What is left over after his or her death can go to any surviving siblings.

Sometimes, when making a will, parents think that, because the dependent family member will be receiving a pension and accommodation provided by the government, there is no need to make any provision for them in the will. However, children with disability have a legal entitlement under law to share in their parents' estate, and they or someone on their behalf could challenge your will in court if inadequate provision is made for those children.



The MALSSA Disability Rights Advocacy Service Inc has produced a booklet on these topics, titled *Caring for their future* (www.malssa.org.au/brochures/MALSSA_ENGLISH.pdf). Telephone 8351 9500 or email malssaadmin@malssa.org.au and ask them to send you a copy. The booklet is available in audio format. Contact the Legal Help Line for free legal advice and information on 1300 366 424.

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Estate planning tools

Your will

There are several useful tools when planning your estate. The basic tool of estate planning is your will. If you die without a will, you are said to have died 'intestate'. Dying intestate means you have left no lawful instructions as to how you want your estate to be distributed. In such case, the laws in each State and Territory in Australia will determine who will inherit the assets of the estate. This determination can result in a distribution contrary to your wishes.

It is important to ensure that the will is correctly drafted and takes into account any relevant estate planning strategies. It is best to obtain help from a solicitor or other qualified person to ensure you get defined what you want and need.

Powers-of-attorney

A **power-of-attorney** is a legal document that appoints a person or organisation to act on your behalf. By appointing an attorney, you give the attorney the authority to make business and financial decisions for you, sign documents and generally act in your best interests. Your attorney could buy and sell shares for you, for example, and manage your finances and pay your bills.

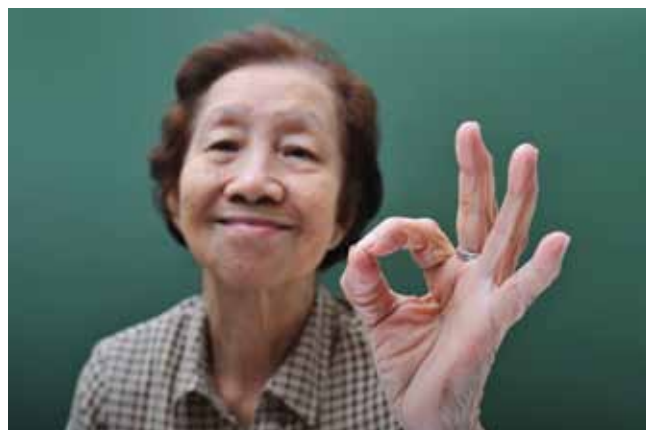
There are two main forms of power-of-attorney: general and enduring. The difference between the two forms is simply that **general** powers-of-attorney are automatically cancelled (or 'revoked') if you become mentally incapacitated either through age or brain injury. **Enduring** powers-of-attorney, however, remain in force if you are unable to make your own decisions for any reason.

Suppose, for example, that a husband and wife have enduring powers-of-attorney for each other; if one becomes mentally incapacitated due to an accident, the other can act on his or her behalf. If the enduring powers-of-attorney did not exist, then

the capable spouse would need to obtain authority through the Guardianship Board.

In general, the authority your attorney has to act on your behalf is quite broad; however, you can limit the attorney's power to a specific task if that's what you'd prefer. You can also specify when the power-of-attorney comes into effect; for example, if an illness or accident occurs that leaves you unable to make your own decisions. You can revoke your enduring power-of-attorney at any time while you still have mental capacity.

While the enduring power-of-attorney allows someone to make financial decisions for you, an enduring **power-of-guardianship** allows the guardian to make medical and personal decisions. The guardian may authorise medical and dental treatment, for example, or decide where you live. You can nominate in the document the 'functions' for which your guardian can make decisions for you.



You may also wish to consider having a back-up executor, attorney and guardian nominated (in each document as appropriate) to cover you in the event of your nominated person being unable to act for any reason.

Visit the web sites at www.lsc.sa.gov.au and www.lawhandbook.sa.gov.au.



Culture, perceptions elements in care

The National Ethnic Disability Alliance (NEDA) is the national peak organisation representing the rights and interests of people from non-English speaking background (NESB) with disability, their families and carers throughout Australia.

NEDA estimates that one in every four people with disability is from either first or second generation NESB, representing approximately 1 million people across Australia. NEDA also estimates that there are at least 640 000 NESB Australian carers. People from NESB with disability and their carers have a lower service usage rate and may face additional barriers.

The definition of a carer varies significantly because of cultural and linguistic factors. Carers from NESB may not readily identify as 'carers' and they are a significant proportion of the hidden carer population. NESB carers report the term 'carer' as foreign to them, that they consider the carer role as a 'natural duty', as of a mother caring for her children, children caring for their parents, brother or sister caring for their siblings and so on.

There is a difficulty associated with using a Western model of care to describe non-Anglo-Australian care relationships. Australian government programs tend to focus on the concept of a 'primary carer' even though some family structures may not clearly support the concept of a single resident caregiver: for example, families that share care responsibilities between resident family members, with non-resident family members or friends.

An often falsely perpetuated myth of culturally diverse communities is that 'they take care of their own'; that is, the support provided by the family and community is sufficient and external support—particularly from service providers—is not required. While some ethnic communities are well-resourced and can provide excellent support to individuals and families, the reality

for many people with disability from NESB is that they and their families face discrimination from their own communities.

Prejudices and misconceptions regarding disability present in Anglo-Australian communities are equally evident in those of NESB, relating particularly to high levels of stigma surrounding disability and mental illness, and fear of a lack of confidentiality, particularly in smaller communities.

Too often services seem unable to accommodate linguistic and cultural diversity of consumers. Using interpreters and publishing material in languages other than English are basic mechanisms to work towards access equity. Staff can be trained to incorporate cultural difference, diversity and understanding of the nature of the person's experiences when delivering services; bilingual/bicultural workers are able to overcome some of these barriers.

Financial pressures are exacerbated since immigrants with disability have to wait 10 years before being eligible for the Disability Support Pension (DSP). The DSP, however, is often an eligibility criterion for essential disability services such as post-school programs or programs for appliances and equipment. Further, some NESB carers are unaware of their entitlements to carer payments and carer allowances.

NEDA encourages disability support and care services to embrace an inclusive vision where cultural diversity and disability rights are valued as essential aspects of the service system. People from NESB with disability and their carers are encouraged to join our national network to receive information, raise and contribute issues and be empowered through peer advocacy. Visit NEDA's website at www.neda.org.au.

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Making life easier through assistive technology

The act of opening a jar, turning a tap or standing up from a toilet can be painful and frustrating for some people with disability. The world of assistive technology continues to grow and there are many useful gadgets now available to help make these everyday tasks easier and safer.

Disability Service's Independent Living Centre (ILC) is a community service that provides information and advice on assistive technology (equipment) to help individuals improve their quality of life and maintain their independence. The free service is staffed by occupational therapists and is available to all members of the public.

You can phone or email staff to get personalised advice and information, or make an appointment to visit the centre to see and trial first-hand a range of equipment. With the guidance of an experienced professional, visitors to the ILC can discover the equipment and techniques that will best suit them to help with everyday tasks.

Walking frames, wheelchairs and scooters (gophers) are among the items on display in the mobility section of the centre. Many people love cooking, and an accessible kitchen is on display along with a range of cooking utensils and slicing, peeling and cutting aids. Large-handled cutlery and angled knives may be beneficial for those who have trouble grasping.

A personal alarm/emergency call system can provide peace of mind for those concerned about relatives or friends living alone.

The bathroom is often an area of great safety concern. Items such as height-adjustable shower chairs, toilet seat raisers, grab rails and



A woman with grip problems uses a kitchen aid knife, with the guidance of a member of the ILC staff.

slip-resistant applications can help to prevent accidental slips, trips and falls.

Equipment at the ILC ranges from complex mobility scooters, electric beds and recliner chairs to simple household gadgets such as long-handled pick-up sticks, book and card holders, and even devices to help put on lotions and creams in hard-to-reach places. It can sometimes be hard to accept the need for assistive devices but it is important to realise that these items can be vital in assisting people to stay safer and more independent in their own homes for longer.

Brochures, fact sheets and written product information are available for all equipment areas, including specific item descriptions, supplier details and approximate costs.

Contact staff at the Independent Living Centre on 1300 885 886 (SA/NT) or 8266 5260 or email ilcsa@dfc.sa.gov.au for more information or to make an appointment.

The equipment display is located at 11 Blacks Road, Gilles Plains. You can preview the catalogue online at www.ilcaustralia.org/contactstates.asp?State=SA.

Incontinence: sometimes challenging

Incontinence is a common health issue in our community, affecting over four million Australians from all age groups.

Many carers find caring for a person with incontinence to be a challenge. Incontinence often increases a carer's workload and continence products may be costly. Carers are often family members (but sometimes friends and neighbours) who provide support to children or adults who have disability, mental illness, a chronic condition, or are frail and aged.

It is important to seek help for incontinence from health professionals. Appropriate treatment and management strategies for it can really make continence issues, and life, more manageable.

Key messages for carers

Incontinence needs medical attention in the same way as other health conditions.

Continence resources and community help are readily available.

Continence funding schemes are available for some people to help with the cost of continence products.

Carers need care, too; the health of their own bladders and bowels is important.

Continence help is available from your local GP and/or medical specialist, and from Community Continence Services—in the metropolitan area (for example, Royal District Nursing Service (RDNS), the Repatriation General Hospital, and Resthaven Marion, Paradise or Elizabeth) and in country areas through the local community health service.

Continence Resource Centre

The Continence Resource Centre (CRC) is located at the Independent Living Centre. The CRC provides information on community continence services, continence funding



schemes, and information on the large array of continence products and where they can be bought.

The Continence Resource Centre also has a range of continence information sheets available: *Continence Products*, *Key Points When Managing Incontinence*, *Faecal Incontinence*, *Managing Incontinence when Travelling*, and *Skin Care and Incontinence*.

The Continence Resource Centre is located at the Independent Living Centre, 11 Blacks Road, Gilles Plains. Contact them by telephoning 8266 5260 or emailing continence@dfc.sa.gov.au.

Visit www.sa.gov.au/disability/crc for online information sheets on these topics.

National Continence Helpline

The National Continence Helpline (telephone 1800 33 00 66) is a free confidential service available to all Australians. The Helpline is staffed by continence nurse advisors who provide information and advice about bladder and bowel problems. The National Continence Helpline is an Australian Government initiative, managed by the Continence Foundation of Australia, that operates from 8.00 am to 8.00 pm Monday to Friday.

continued on next page

Carers' continence literature

Free continence resources are available from the National Continence Helpline on many different aspects of incontinence.

Specific carer resources include an easy-to-read booklet, *Help for People who Care for Someone with Bladder or Bowel Problems*, providing practical tips about caring for a person with incontinence. There are fact sheets, too, on *Caring for Someone with Incontinence* and the *Young Carers Factsheet*.

Continence and incontinence sites

- **The National Public Toilet Map:**
www.toiletmap.gov.au

This website shows the location of more than 14 000 public toilets across Australia. Information is provided about each toilet such as location, opening hours, baby change rooms and accessibility for people with disability. The National Public Toilet Map is available on any mobile phone with an internet browser, and on Apple's iPhone.

- **The Australian Government Bladder Bowel site:**
www.bladderbowel.gov.au

This website provides general information on bladder and bowel problems, and information on CAPS (the Continence Aids Payment Scheme).

- **The Continence Foundation of Australia:** www.continence.org.au

This website provides information on incontinence for the general public and health professionals, and details about the National Continence Helpline and continence literature resources.

Housing SA wins awards for disability accommodation

The Department for Communities and Social Inclusion has been recognised by peak industry bodies and the public for its recent work for people with disability.

The Disability Housing Project was a winning entry among those nominated for the Urban Development Institute of Australia (UDIA) President's Award. The project won the Civic Trust People's Choice Award under the social category, and the project team was Highly Commended for professional excellence in housing for Leading Housing Solutions in the Australasian Housing Institute (AHI) Awards.

The project is a testament to state and federal commitment to constructing purpose-built housing and supported accommodation for people with disability and those who care for them. The project highlights sound application of Commonwealth funds, with team collaboration between Housing SA and Disability Services, and the contribution from chief design consultant Studio 9 Architects.



The delivery of these houses in the metropolitan area and regional locations throughout the state means our most vulnerable people can better connect with the community, promoting the involvement of family and friends.

Home and Community Care looks to future

Responding to the needs and choices of Home and Community Care (HACC) eligible carers: helping them stay connected and providing support through periods of transition.



The Home and Community Care (HACC) Program is jointly funded by the State and Commonwealth Governments to provide low-level services for frail older people, younger people with disability and their carers—all with the aim of helping them to remain living at home and preventing early admission to residential care.

The State Government Disability, Ageing and Carers (DAC) branch within the Department for Communities and Social Inclusion manages the program in South Australia.

The HACC program provides carers with counselling, support, information and advocacy services and respite care. HACC recognises that care situations can change suddenly. This change can mean that carers are no longer eligible for the social supports and connection to the community that are part of the HACC Program. HACC carers, through consultations, identified the need for early preparation and aftercare when their caring role ceased. During their time of caring, they had focused on their caring role, often to the detriment of their own health and wellbeing.

The carer feedback led DAC to recognise that a preventative approach is needed, integrated into current work practices, to enable and support HACC-eligible carers. Such an approach will need to enable carers to stay connected to their community, maintain control of their lives, and maximise their own physical, emotional and mental health and wellbeing while receiving HACC carer services.

When carers transition through the stages of their caring role, their natural networks, community connections and support systems will have remained as intact as possible.

DAC has engaged the consultancy firm of

HOKJOK to research and develop a framework to prepare HACC carers during the active phase of their caring role for the end of that role. The framework will take a 'whole life' approach to supporting HACC carers, and will explore planning for the future to support carers to build on and maintain involvement in the different realms important in their life. While HACC is not funded to provide all the support needed, the opportunity to link and refer to other programs will be a component of the framework.

HOKJOK will consult with HACC-funded agencies, and current and past HACC-eligible carers who may or may not be receiving formal HACC services. There will be specific consultations with Aboriginal and Torres Strait Islander carers, and those with culturally and linguistically diverse backgrounds.

An advisory group has been established and two meetings have been held. A survey will be made available online for those individuals and groups being consulted, located on the HACC web pages at www.sa.gov.au/seniors/hacc. The project report is due in early 2012 and a summary of the project's findings will be made available on the HACC web pages by June 2012.

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Self-managed funding: delivering greater choice in care



Self-managed funding is a recent State Government initiative designed to give people with disability more control over the funding allocated for their support needs.

As of November 2011, there were 51 people with disability in South Australia managing their own funding. The early success of the initiative shows the importance of the scheme to people living with disability and their families.

As self-managed funding participant Trish Spargo explained:



Bryan Foley and Trish Spargo

For many years, I accessed specialist disability services for assistance managing my rheumatoid arthritis.

This help included assistance with showering, dressing, meal preparation, shopping, laundry, ironing, and house cleaning. However, many of my support needs can be met by mainstream community providers and don't require a team of specialised disability workers.

Under self-managed funding arrangements, I'm given the choice to purchase laundry and ironing services, house cleaning services, car cleaning services, and have my groceries delivered, using local businesses in my local area. These services complement the personal care support I receive from my specialist disability service provider.

I'm no longer made to feel different from my friends and family through a total reliance on the specialist disability service system. I have real choice about who I purchase services from, and as such, I have a much greater connection to my community and a sense of independence.

Further information about Phase One: Self-managed Funding Initiative is available from Disability, Ageing and Carers.

Telephone 8415 4389

Email DFCDisabilitySelf-ManagedFunding@dfc.sa.gov.au

The self-managed funding facilitators can answer more specific inquiries from clients and carers on telephone 8372 1479 or at email DFCSelfManagedFacilitator@dfc.sa.gov.au.

Trish's partner Bryan has also noticed the benefits of her self-managed funding arrangements: 'Rather than care being imposed on us, it has given us choice as a couple about how we manage our home and life'.

Self-managed Funding Project Team

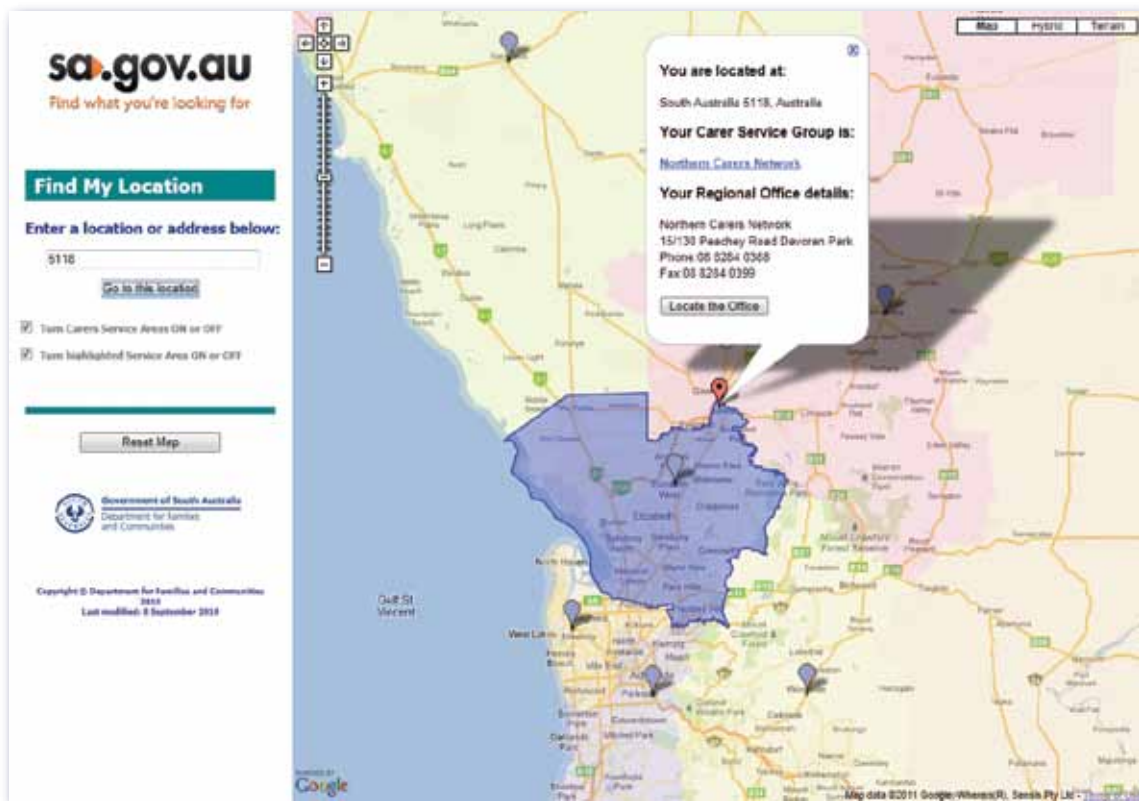
Disability, Ageing and Carers

Telephone 8415 4355

Email

DFCDisabilitySelf-ManagedFunding@dfc.sa.gov.au

Taking care of carers: the Gateways Project



A sample map showing the location of a carer service based on the postcode 5118

Accessed 31 October 2011

The Gateways Project aimed to raise awareness about carers with health professionals so that carers were encouraged to seek information and support early, instead of when faced with a crisis.

Working mainly with general practitioners and other health professionals was a high priority because of the negative health effects associated with caring, and the unique opportunity the medical sector has to monitor carer health and encourage carers to seek help and support for themselves. The project also worked with other government departments and non-government organisations, including pharmacies, to raise carer awareness.

Caring can carry significant emotional, physical and economic consequences. We know, for example, that carers experience significantly worse health than non-carers.

I struggled along by myself for ages until my doctor suggested I call the carer support service. They were wonderful and understood what I was going through. I wish I had known about carer support years ago; it would have made such a difference.

Carer, 65-years-old

From the Gateways Project, a tool (the Carer Support Services Search) became available that will be immediately useful to you if you are a carer. The search tool, which includes a search map, is now featured on the South Australian government web-based carers portal. See it for yourself at www.sa.gov.au/carers. Type in your postcode (as above) and the website will identify your local carer service, show you its location on the map and provide you with contact details.

Office for Carers
Telephone 8207 0454
Email dora.martino@dfc.sa.gov.au

The National Carer Strategy

Australia now has a National Carer Strategy which, with the Strategy and the Carer Recognition Act 2010, is one of the two components of the Australian Government's National Carer Recognition Framework.

The strategy has been developed in consultation with state and territory governments, carers, service providers and peak bodies. It was launched on 3 August 2011 by the Australian Commonwealth Government Ministers Macklin, Roxon and Butler, and Parliamentary Secretary McLucas.

The National Carer Strategy contains a vision, an aim and six important priority areas for action: recognition and respect, information and access, economic security, services for carers, education and training, and health and wellbeing. These priority areas specify how the contribution of Australia's carers will be better valued, supported and shared.

The strategy delivers on the Australian Government's commitment to better respond to the needs of carers. There is now an ensured opportunity for carers to take part in all aspects of society, including the chance to participate fully in work, community and family life.

Funding delivered under the National Carer Strategy includes \$60 million in new funding over the next four years, of which \$1.6 million is for a national and targeted campaign to raise awareness of the role of carers.

The National Carer Strategy builds on measures that the Australian Government already provides for carers and complements reforms to improve supports provided through the aged care, disability, mental health, primary health care, hospital and community care systems.

Visit www.fahcsia.gov.au for more information about the National Carer Strategy.

South Australian Carers Act review

The South Australian Carers Recognition Act 2005 (the Act), passed in December 2005, requires that, as soon as practicable after the fifth anniversary of the commencement of the Act, a review be undertaken into the operation and effectiveness of the legislation. See the Act and information about the review at www.sa.gov.au/carers. The Office for Carers has undertaken the consultation component of this process, hosting sessions for carers and service providers in Adelaide, the Barossa, Mount Gambier and Port Augusta.

A discussion paper and survey were developed and widely distributed to gain the opinion of as many carers and service providers as possible about the operation and effectiveness of the Act. The paper and survey were also available on the Office for Carers website.

Consultation sessions were well-attended, particularly by carers, and many surveys were submitted online and by post. Communities were keen to engage in the process. Both carers and their service providers were pleased to have an opportunity to learn more about the legislation, to comment on it and its effects, to make suggestions about it and to talk generally of their experiences as carers or their experiences in providing services to carers. The process of the review in itself has raised the level of discussion about, and awareness of, carers in our community.

A report will now be prepared based on the information gained from these surveys and the consultation sessions. The Minister for Communities and Social Inclusion will table this report before both Houses of Parliament.

Office for Carers

Telephone 8207 0454

Email dora.martino@dfc.sa.gov.au

Disability Services: around the regions

Adelaide Hills

Mt Barker 'MyTime'

I really look forward to our group time, knowing you can have a couple of hours—time out—while your children are being cared for right next door by professionals and to do something different, have a cuppa and a chat.
MyTime parent

'MyTime' is a national program funded by the Parenting Research Centre but delivered locally. Peer support groups provide an opportunity for carers to socialise and relax. MyTime lets carers share experiences about the rewards and challenges of caring for a child with disability or chronic medical condition.

MyTime provides a crèche for pre-school children (including siblings), giving carers a well-deserved break to enjoy programmed activities or simply chat over a great coffee and morning tea. Members join in planning the sessions. Information sessions have not been a popular choice for the carers, many of whom said they prefer to have time-out from being overloaded by disability information. So, the group has evolved to suit the needs of participants. The regular massage therapy is always popular.

The MyTime group heads out each term on a childless evening adventure: a dinner and movie night, or a bus ride to town for ten-pin bowling. Occasionally, we organise a family day so partners, school-aged siblings and extended family members can join in. We have been to Cleland Wildlife Park and also made a gourmet lunch in the local community garden's pizza oven.

MyTime member comments include: *It gives you the opportunity of the fun stuff, but*

most importantly some strong friendships and support with other families going through similar situations, that you wouldn't normally have on a regular basis with young children.

We have done some fun activities which have been relaxing and enjoyable, to do things that you don't get time for any more or try something different such as crochet, craft, drawing, making cards, cooking, massage, make-up sessions, jewellery making and the list goes on. Also not forgetting some memorable nights out to tea, movies and ten-pin bowling.

I think it's great to do new things, have some time out, meet new people and talk to other mums in a similar situation.

The Mt Barker MyTime group formed just over two years ago, growing steadily in popularity to capacity at 12 regular attendees and a waiting list. Twelve children

attend the crèche. Our play helpers provide the children with quality play experiences including a sandpit, swings, water play, activities in the garden that exercise gross motor skills, table-top activities and playing with a range of educational toys. Therapy goals such as turn-taking skills and using appropriate communication methods are reinforced.

My experience with [the group] has been very positive and rewarding. It has given me friendships with other mums going through similar situations, with every one of our children, all different ages and having different disabilities. We all share the common bond that life is just not the typical—offering support, ideas and camaraderie.

Victor Harbor

Once a week, a small group of young people work together imaginatively to build friendships and social skills. They are the founding members of Victor Harbor Disability Services 'Lego Club'.

Lego Club began in August 2011 to provide a social learning space for children with Autism Spectrum Disorders (ASD) who were no longer eligible for early intervention services. The group

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has members aged 6 to 12 years, including some siblings of children with ASD who act as peer mentors. Club members are supported by trained facilitators who model appropriate social behaviours, help group members to problem-solve and resolve conflicts, and provide support for emotional regulation. This unique combination of Lego® therapy, peer mentoring, and video modelling is a first within Disability Services.

Families involved in Lego Club are impressed with the enthusiasm shown by the young members. 'We haven't been able to stop him from counting down the days until the next group,' said one parent. 'He reminds us how many sleeps to go each day!'

Group members have shared their enjoyment over having a place to belong. 'Lego Club is the first club I have been in,' said Jeffrey, a peer mentor in the club. There are encouraging signs of friendships being continued outside of the group, 'I know some of these kids from my school, but I didn't play with them before,' explains Lachlan.



The Victor Harbor Lego Club has adopted the key principles of Lego® therapy and added some local flavour to their activities with an exhibit in the local Port Elliot Show during early October. Get more information from the Victor Harbor Disability Services Team, on 8552 0600, or at email erin.anear@dfc.sa.gov.au.

Onkaparinga area

The 'Fun and Friendship' group is a social, recreational and friendship group for people over 20 with intellectual disability living in the Onkaparinga area. They meet fortnightly on a Sunday afternoon.

Fun and Friendship is based at the Woodcroft Community Centre; however, most of the events and activities involve going out. Group members go to festivals and events together, to the movies, bowling and mini-golf, and to places in town like the Adelaide Central Market, among other things. The aim of the group is for people to increase their friendship networks, get involved in community and recreational opportunities, and for participants to be involved in making decisions about what the group does. Community Choices organises and provides support for the group. Contact the Disability Services Christies Beach office on 8384 7299 for more information.

Mount Gambier

The Rotary Club of Mount Gambier and staff at the local Disability Services office joined to host regular Family Fun days for children with disability and their families. The first event was held in early 2011, attended by over 70 people. Families, children and their siblings enjoyed varied activities including arts and craft with children making a rabbit mask and decorating an Easter bag for the Easter egg hunt.

Children also spent time playing on the 'Large' games provided by Mount Gambier City Council, including the enormous noughts and crosses, chess, and snakes and ladders; all the games were a hit with the children.

New friendships were made by adults and children, giving families chances to connect socially. Staff overheard newly acquainted parents making plans to meet for coffee.

The Rotary Club of Mount Gambier is committed to supporting this event with another fun day planned for December 2011. Contact the Mount Gambier office on 8735 1800 for further information.

Gilles Plains and Regency Park

Learning to Cook

Staff from two regional offices have been involved in a community development initiative

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responding to a recognised need for people with intellectual disability to increase their daily living skills.

A cooking group began in April 2011 to teach participants basic cooking techniques, provide information on healthy eating and enable participants to master some of the recipes to cook them at home.

The group ran for 10 sessions and was a great success. Graduating participants each received a pictorial recipe book to take home.

Participants in the group made their own individual positive gains, including using a knife safely, feeling confident in the kitchen, presenting food attractively, applying hygiene skills and keeping the area tidy, speaking up and asking questions, working in a team, making new friends and, of course, cooking simple and nutritious meals.

The cooking group's next session began in September 2011, focusing on different cultural cuisines. This group saw participants, currently living independently, or working toward it, increase their cooking skills and awareness of healthy eating.



Gilles Plains

Parenting With Confidence

The Gilles Plains Early Childhood Program offered parents a 'Parenting With Confidence' program in 2011, based on the parent education program, *Circle of Security Parenting Training*© DVD. This program focuses on strengthening parent/child relationships by helping parents to better understand their children's needs and how these needs affect their child's behaviour. It also teaches how parents can respond to those needs and behaviours so that children can grow up feeling secure and confident.

The Circle of Security Parent Training integrates over 50 years of early childhood research into a DVD-based teaching program. Developed by a team of psychotherapists from the United States of America, this program draws upon:

Decades of university-based research [that] have confirmed that secure children exhibit increased empathy, greater self esteem, better relationships with parents and peers, enhanced school readiness, and an increased capacity to handle emotions more effectively when compared with children who are not secure. [www.circleofsecurity.net, accessed 1 November 2011].

Parent participants told us:

This course has given me enormous understanding of myself and my children.

The program was very beneficial in teaching me how to 'be with' my child and help them to organise their feelings, which down the track will hopefully make their emotional life easier.

This program has allowed me to better understand my child's need. When I look at my child's behaviour, I feel I have a better understanding of what his

behaviour means and what he is trying to communicate. By better understanding this, I feel he has calmed and become more secure.

Parenting With Confidence will be offered to parents of Gilles Plains Early Childhood Program again in 2012. Contact Bronwyn Skein by phoning 8366 7300.

Salisbury

Young Men's Social Group

The group meets every Wednesday from 3.00 to 5.00 pm at the Twelve25 Salisbury Youth Enterprise Centre. The group is now well-established and provides a place for young men aged 15 to 25 to go and feel part of the

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community. The young men relax and talk if they wish, or play cards, eight-ball, basketball, indoor carpet bowls or play on the Wii. A vegetable garden is tended by some members. Contact Bernie Fairhurst, Disability Services Salisbury on 8282 5500 for more information.

Boccia comes to Port Pirie

Port Pirie Disability Services joined with other services in a 'Come and Try Boccia Day'. Participants ranged in age from primary school children to people in their mid-50s.

Boccia is a skill-based, strategic and exciting sport that can be played by people of all ages and abilities. Top players can qualify to play at national and international levels, including the Paralympics. Games can be played as singles, pairs or in teams. At all levels, players are seated and throw coloured balls as close as possible to the jack. The balls can be propelled with hands, feet or, if a player's disability requires it, with an assistive device such as a ramp, or mouth or head pointer.



The very popular event led to a weekly competition. We secured funds from Wheelchair Sports SA, and the Office for Recreation and Sport, to contract a boccia facilitator for Port Pirie for the first six months of the program. People also wanted an evening/weekend competition for people in a day or work option to join in after hours. Contact Glenys Dreyer or Natalie Fisher, Disability Services Port Pirie, on 8632 0155 for information.

Regency Park

Western Shed

The Western Shed program is a chance for men and women with acquired brain injury to join a woodwork group of up to 10 people, meeting at the Parks Community Centre.

The participants make wooden products for themselves, their families and friends, including

hat and coat stands, coffee tables, magazine racks and furniture restoration; one man is even restoring an antique fireplace surround.

The supervised program runs once a week on Wednesdays from 9.30 am to 2.30 pm. A short induction is important before joining the program to become familiar with the workshop.

Contact Mick McIntyre on 8348 6000 or Westley Tully on 0403 472 996 for information.

Tea Tree Gully

Living Skills Program

The Living Skills Program is offered at the Jubilee Community Centre. It is facilitated by a Community Development Officer from the City of Tea Tree Gully and funded by Disability Services. The program has been operating since 2002 and runs monthly for 2 to 3 hours, with regularly scheduled half-day and full-day outings. Up to 12 people with mild intellectual disability can be involved in a social afternoon with fun and educational activities that increase self-esteem and social confidence. People also learn how to live independently and eat healthy meals. The facilitator responds to the participants' skills and interests, increasing the level of challenge to match growing capacity. Contact Alice Trott at the Northern Adelaide office on 8366 7300.

Aktion Club

The Aktion Club is a service club for people with disability and is supported by Kiwanis. The Tea Tree Gully Aktion Club has membership of about 20 people with disability. During the evening, a business meeting is conducted by the participants with ongoing support from a Kiwanis member. Some months, the Aktion Club will do a service to the community, raise money or have an outing that all enjoy. Many participants are elected by their peers as office bearers for a period of 12 months. There is often a guest speaker or an activity, followed by supper. Contact Julie Harms in the Northern Adelaide office on 8366 7300 for information.

Library resources: carers and caring

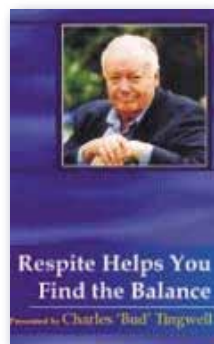
You may borrow many Disability Services publications, and other material and resources, free-of-charge from the Department for Communities and Social Inclusion (DCSI) Library and Information Service (Disability Collection). We're located at Strathmont Centre, 696–710 Grand Junction Road, Oakden. It's a good idea to email us at disability.library@dfc.sa.gov.au or telephone us on 8266 8556 from 9.00 am to 3.00 pm weekdays, so we can talk to you about your inquiry before you make the journey.

Communication for carers: family carer support materials: developing carer skills: a resource booklet, by Pat Gallasch and Annette McKee. Department of Human Services: Carers Association of SA Inc, 2001. The Library has other related titles by Gallasch and McKee.

Children as carers: an overview of literature and projects on children as carers, by Milivoj Oreb. Carers Association of SA, 2001.

Balance the care [DVD], presented by Julie McCrossin. Developed by Carer Respite Centre Southern Region, Prahran, Victoria. Ideas that Work, 2001. Offers an insight into the situations and emotions that people who care for others live with every day. It is broken up into 11 different sections and is an honest exploration of issues such as loss, grief and isolation.

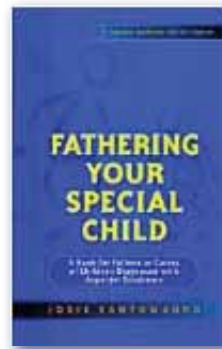
Respite helps you find the balance [DVD]. Canberra, Commonwealth Department of Veterans Affairs, 1999. This DVD is presented by Charles 'Bud' Tingwell, who was himself a carer. Other carers tell their stories and how vitally important respite care is to the wellbeing of both carers and the person for whom they care.



Aged care: communicating with family and carers [DVD]. Director, Stephanie Charewicz; writer, Cath Ferla; senior producer, Pru Burns; executive producer, Simon Garner. Bendigo, Victoria, Video Education Australasia, 2010. This program presents approaches and interpersonal skills for the successful care of older Australians. It discusses the combining

of informal care arrangements by family with formal aged care services.

Fathering your special child: a book for fathers or carers of children diagnosed with Asperger syndrome, by Josie Santomauro, Carla Carino,



illustrator. London: Jessica Kingsley, 2009. This book offers a fun and accessible introduction for the father or carer of a child diagnosed with Asperger syndrome. It is intended as a support tool in the initial period after diagnosis and addresses questions or concerns that a dad might have. See

also the books on mothering and on being a grandparent for a 'special child'. The Library has other related titles by Santomauro.

A different kind of perfect: writings by parents on raising a child with special needs, edited by Bernadette Thomas and Cindy Dowling. Boston: Trumpeter, 2006. The writings collected in this book are grouped into chapters reflecting the progressive stages of many parents' emotional journeys, starting with grief, denial and anger and moving to acceptance, empowerment, laughter and even joy.

Protecting children & young people with disabilities: a booklet for parents and carers, by the South Australian Department for Families and Communities. Adelaide: 2005. A first step to increasing community awareness of abuse and neglect of children and young people with disability. It has practical information about keeping children safe as they make that inevitable move into the wider community.

Getting in touch with us



We have many ways for you to contact us. We welcome your questions and feedback through telephone calls, emails and visits to our offices.

Disability information and referrals line 1300 786 117

Telephone this number to ask questions or make a referral for services. Customer Information staff will do their best to help you. We'll ring you back if we can't answer your questions straightaway.

Information by email

Email questions to disabilityinfo@dfc.sa.gov.au and we will respond.

Information on the website

Visit www.sa.gov.au/disability to find a wide range of information sheets (select 'Information and Publications') plus links to other resources and sites.

DCSI Library and Information Service (Disability Collection)

You may borrow many Disability Services publications, and other material and resources from the library, free-of-charge, by telephoning 8266 8556 from 9.00 am to 3.00 pm weekdays or emailing disability.library@dfc.sa.gov.au.



Offices

There are Disability Services offices throughout South Australia. The full list can be seen online at www.sa.gov.au/government/entity/1646/About+us+-+Disability+Services/What+we+do/List+of+our+services/Disability+Services+offices.

Independent Living Centre

The Independent Living Centre is located at 11 Blacks Road, Gilles Plains SA 5086.

Our opening hours are 9.00 am to 5.00 pm, Monday to Friday.
Telephone 1300 885 886 (SA/NT callers only) or 8266 5260
Fax 8266 5263
Email ilcsa@dfc.sa.gov.au

Accessible off-street parking is available. Bus routes from central Adelaide are 500/501 or 208 to stop 28 on Sudholz Road.

The Continence Resource Centre

The Continence Resource Centre is located at the Independent Living Centre, 11 Blacks Road, Gilles Plains SA 5086.

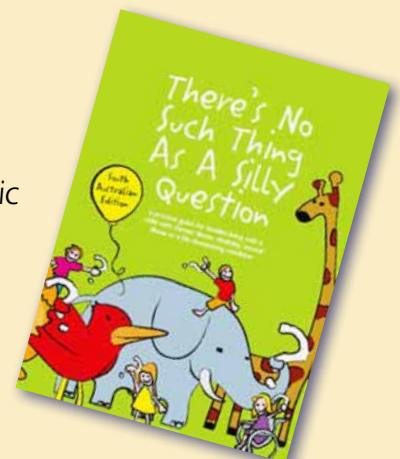
Our opening hours are 9.00 am to 5.00 pm, Monday to Friday (by appointment only)
Telephone 1300 885 886 (SA/NT callers only)
Fax 8266 5263
Email continence@dfc.sa.gov.au

Did you know?

... there's no such thing as a silly question? No, really!

Download a complimentary copy of *There's No Such Thing as a Silly Question: a practical guide for families living with a child with chronic illness, disability, mental illness or a life-threatening condition*, from www.wchfoundation.org.au/Content.aspx?p=121. The book's aim is to assist parents to find their way around the medical and community systems.

Contact the WCH Foundation on 8464 7900 or email nosuchthing@wchfoundation.org.au for more information.



Aboriginal program award

The Northern Carers Network (NCN) won an Outstanding Initiative Award for its *Aboriginal Grandparent Support Program* in the 2011 South Australian Carers Recognition Awards.

The program's success lies in its service delivery model that supports strengthening the whole family. NCN takes an holistic approach to carer support that develops community capacity across all its programs.

The NCN is strongly connected to and respected by the local Aboriginal community, supporting and linking them to appropriate services and programs. NCN has successfully created opportunities for Aboriginal grandparents, carers and their families to embrace traditional cultural and spiritual healing practices, with the contribution of Ngankere, traditional spiritual healers.

The high incarceration rate of Aboriginal people, high levels of dependency on the system and increasing levels of mental illness, particularly in the northern metro region of Adelaide, are affecting the health and wellbeing of our Aboriginal community.

A community development approach to carer support has a direct positive effect on the health and wellbeing of Aboriginal grandparents and carers and is effectively 'Closing the Gap' for the Aboriginal community in the northern district. The program provides



activities for young carers, parents, carers, grandparents, Elders and family members. Aboriginal carers have said that without NCN support they would not know where to turn.

Intergenerational activities provide greater respite options; increase confidence and self-esteem; reduce isolation; create opportunity for friendships, volunteering and skills development; and give all generations a place and role in their community.

Intergenerational relationships within and between families and the wider community are the core foundation and network that are expected to support and carry the needs of our Elders and people with disability. Community development effectively creates resilience and powerful carer support through the values that are deeply embedded by our community and that will continue to guide us forward into the future as we grow.

Sharon Hoffman

Manager, Aboriginal & CALD Programs, Northern Carers Network

Telephone 8284 0388

Email sharon@ncnw.org.au

We hope you enjoyed the latest edition of *infoLink*.

And, now that you've read it, perhaps you'd like to pass it on to others. Your neighbours, friends, family and carer(s), might find the articles interesting, too.

Remember, there are always *infoLink* copies online if you want to re-read anything, at: www.sa.gov.au/disability/publications.

Share the wealth and pass it on! Or, tell people about the website versions, including a text-only copy.

