

# National NoticeBoard

Newsletter of Australian Association for Families of Children with Disability (AAFCD)

## Remember When

What do you remember most about those first few years in and amongst the time of diagnosis or identification of your child's disability? What do you remember most about your initial searches for information and support? With the benefit of hindsight, what advice would you give to today's 'new' parents of children with a disability?

For all new parents of children with a disability in the future, are there obvious ways that governments, professionals and organisations can provide better information and support in those initial years?

For me, I remember my emotions were all over the place as my son Ben's issues became clear and we started on the long road to a diagnosis of Rubinstein-Taybi syndrome and autism spectrum disorder.

It is difficult to put into words the depth of emotions I felt during this time—numbness, fear, isolation, loneliness, anxiety, confusion, overwhelming shock and a deep sadness which words just cannot describe. There was all this and more. I cried a lot.

I remember feeling extremely frustrated by how difficult it was to find out basic information about services and support. You expect doctors and other health professionals to know everything there is to know, but due to their busy medical roles it is not possible. Getting information and support is a bit 'hit and miss' and a lot depends on whether the professionals you see in those early days are knowledgeable about the broader service system.

Some professionals see themselves as active information links for families. They make it their business to learn about the broader disability support system and provide us with information and encourage us to follow-up and seek additional support.

It's also not just about the content of information, but the way it's delivered and packaged. Professionals need to be able to 'tune-in' to where we are at emotionally, and understand the best ways of encouraging and supporting us with information.

As a resident of rural Victoria I was suspicious that any information from organisations based in Melbourne or Canberra wouldn't be relevant to me and my town. It took me longer than you might expect to find out about the Victorian Association for Children with a Disability and their free publication, 'Through the Maze: A Guide to Benefits and Services for Families of Children with a Disability in Victoria'.

The version of Through the Maze that was around at that time was a dense 30 page booklet, packed with specific information. To some new parents, myself included, it was a very daunting and intimidating publication. I remember opening it and thinking, 'Do I really have to know all this?' I shut it almost straight away and thought, 'I'll read that later, I'm not ready for that right now'. I was suffering from what I now understand to be a very common problem for us parents, INFORMATION OVERLOAD!

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### Your Wisdom?

If you haven't yet seen the draft of our new 'Helping You and Your Family' booklet, and you have the time to read it and provide us with your feedback, please let me know via email: [helenj@aacfd.org.au](mailto:helenj@aacfd.org.au) or leave a message with your contact details on the AAFCD answering machine, freecall 1800 222 660.

Between you and AAFCD's 5,000+ other members across Australia, there is plenty of experience and wisdom about how to best help parents in the early years, and I'm keen to ensure that as much of that wisdom as possible is included in the new booklet.

Helen Johnson, AAFCD Co-ordinator

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AAFCD Co-ordinator, Helen Johnson and family

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Australian Association for  
Families of Children with Disability

I did keep my copy of Through the Maze and some months later, when I was beginning to feel a bit more on top of things, I got it out for another look. I wasn't up for reading it cover to cover, but I scanned it for a few specific topics and made some notes of things to follow up.

As the months rolled on, I found myself using it more and more as a reference guide and a kind of launching pad for following up services and support relevant to me and my family. It had taken a while, but Through the Maze had helped me get started to being an informed parent and able (on my good days) to take charge of initiating and organising things for Ben and our family.

Along the way I also discovered another booklet from the Association for Children with a Disability called, 'Helping You and Your Family: Self-Help Strategies for Parents of Children with a Disability'. I loved this booklet, especially the quotes from parents and the sections on strategies and ideas to think about on topics such as family relationships, diagnosis and dealing with emotions.

All these years later, in my role as AAFCD Co-ordinator, with the help of other parents involved in AAFCD, I've been putting my mind to thinking out how we might produce a national resource for parents that combines the best of the original Through the Maze and Helping You and Your Family booklets.

Last year, a delegation from AAFCD met with the Minister for Family and Community Services, Kay Patterson, to discuss our 'top priority' policy issues for families of children with a disability and what the federal government could do to better assist families with information and support.

One result of these discussions was that the Minister provided us with a grant of \$40,000 to develop our ideas for a new national 'Through the Maze/Helping You and Your Family' booklet.

The new booklet is in a final draft stage. With your support, and some ongoing support from government, corporate and philanthropic sponsors, we are hoping to finalise the booklet and have it published and available in 2006.

We've called it, 'Helping You and Your Family: Self-help strategies and information links for parents of children with a disability'. It's 40 pages long, but designed in a small B5 size with large font and an easy to read style. Hopefully, it's inviting rather than intimidating for new parents.

For those of you who have been around a while and are well linked in with available services and support, the booklet is unlikely to tell you anything you don't already know.

The main target audience for the booklet is 'new' parents of children with a disability in the first few years during and after diagnosis and identification of disability.

It's been a challenge to design a booklet for parents that is relevant and useful across all states and territories, but a very rewarding challenge. Feedback on the draft from parents across Australia has been overwhelmingly positive, with many helpful hints for how to improve the final product. Thanks to everybody out there who has provided feedback so far.

Meanwhile stay tuned to National NoticeBoard and [www.aafcd.org.au](http://www.aafcd.org.au) for further Helping You and Your Family updates in 2006.

Helen Johnson, AAFCD Co-ordinator

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### **New Ageing Carers Announcements**

For more information about a range of announcements for 'ageing carers' by the Prime Minister, the Minister for Family and Community Services and the Minister for Ageing during Carers Week which occurred in October 2005, contact Carers Australia on 02 6122 9900 or your state/territory Carers Association via the national freecall number for Commonwealth Carer Resource Centres on 1800 242 636.

The Carers Australia website [www.carersaustralia.com.au](http://www.carersaustralia.com.au) also has information and links to a range of other Carers Week initiatives, including a substantial report on The Economic Value of Informal Care.

# Continence Issues

Our articles on continence issues, including 'Keeping Our Heads Above Water' in the September 2005 edition of National NoticeBoard, has generated a lot of feedback and discussion from parents, including two examples reproduced below.

In addition to a stream of stories from Victoria pointing to the inadequacy of the Victorian Government's maximum limit of \$450 for assistance with disposable continence products for children under 16, we were also pleased to get some positive stories from Queensland, South Australia and the Northern Territory where parents expressed satisfaction with their state/territory government schemes.

While Victoria recently ranked No. 1 of all states and territories on the social component of an overall liveability index, it is clear that Victoria is far from No. 1 when it comes to continence assistance for families of children with a disability!

We have written to all Premiers and the Australian Government Minister responsible for continence issues, the Hon Julie Bishop MP, seeking information about existing Continence programs for families of children with a disability aged under 16 (states and

territories) and 16 and over (Australian Government), as well as details of any plans to improve these programs in the near future.

We also asked all governments whether they already do, or have plans to, include the capacity to provide up to \$1,500 per year of assistance to families of children with high needs who need to spend more than \$1,500 per year on disposable continence products. At the time of writing, we had only received detailed replies from the governments of Northern Territory and Tasmania.

On the back of the spirit and passion of your stories, along with help and support from other disability advocacy and carer organisations across the country, we will be keeping up the fight for a better deal on continence assistance for as long as it takes to achieve real improvements for families.

**Michael Gourlay, CEO, Association for Children with a Disability (Vic), for AAFCDC**



The Hon Steve Bracks MP,  
Premier of Victoria

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*"Our son Matthew (14) is confined to a wheelchair, cannot walk or stand up on his own. He cannot use his hands to hold objects so he has to be fed all his meals. He cannot assist with dressing or bathing and is incontinent, so he wears continence products 24 hours a day.*

*We currently spend well over \$2,000 a year on continence products for Matthew and I am finding that the cost is rising at a rapid rate as he grows. I've made inquiries as to whether we can obtain more funding as the costs go up, but was advised that it was a standard payment of \$450 per year no matter what.*

*Matthew is in the high support needs category and as a family caring for him at home, it would be a huge help to us financially if the subsidy was raised to \$1,500.*

*I agree strongly with the comments from the 'Frustrated Parent' (in the September 2005 edition of NNB). The government really is compromising the sanity of parents who want to keep their kids at home by not giving them decent financial assistance."*

*Christine Lincoln, Rosebud, Victoria*

*"I am the father of a 12-year-old boy who has an intellectual and physical disability. He attends a Specialist School in rural Victoria and while he has no speech, he does understand his name and the words 'food' and 'drink'. He has AFOs in his shoes and some shoe adjustments to assist him to stand. He took his first unassisted steps just two weeks ago. He also has consistent asthma, eczema and reflux.*

*My son uses continence products 24 hours a day. We supply them for him to take to school. We receive \$450 under the Victorian Gvt. Disability Continence Program for which we are really thankful. In the financial year just ended, we spent a further \$3,220 on disposable continence garments. As he gets bigger, this cost will increase dramatically, as we also have to add additional padding for overnight usage.*

*We are prepared to be out of pocket for continence products for the rest of our lives, but it would be great if the level of subsidy could be raised to at least \$1,500 per year for families with children with high support needs."*

*(Name and address supplied)*

Thanks to everybody who has contributed their stories about continence issues. Please keep them coming. Every story helps with our advocacy to the Australian Government in Canberra on this issue (for young adults aged 16 and over), along with state and territory governments for children aged under 16.

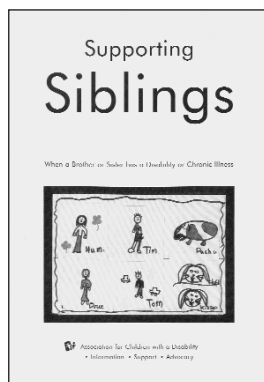
## AAFCD Membership— Strength Together!



AAFCD Membership is FREE for families! Members receive our bi-monthly National NoticeBoard magazine. If you are not already a member of AAFCD, simply fill out the Membership Form on the AAFCD pamphlet and post it to us using our Reply Paid address (no postage stamp required). You can also join over the phone by ringing our freecall number 1800 222 660, or go online to [www.aafcd.org.au](http://www.aafcd.org.au) and complete the online Membership Form. For more information, and to be put in contact with your State/Territory representative, contact Helen Johnson, AAFCD Co-ordinator, on freecall 1800 222 660.



[www.youngcarers.net.au](http://www.youngcarers.net.au)



The booklet 'Supporting Siblings: When a Brother or Sister has a Disability or Chronic Illness' is a publication of the Victorian based Association for Children with a Disability designed to assist parents and service providers with sibling issues.

To request a copy of 'Supporting Siblings' email [mail@acd.org.au](mailto:mail@acd.org.au) or phone 03 9500 1232 or 1800 654 013 (rural callers only). Note: for service providers the booklet costs \$16.50 GST Inc.

## Siblings and Young Carers

Carers Australia has recently produced a *Young Carers pack* which includes information and tips on all aspects of a teenage carer's life, as well as a journal for recording thoughts and emergency care plans, and a relaxation CD.

Young people who have a brother or sister with a disability (who we refer to as 'siblings') are included under the Young Carers banner, along with a range of other young carers such as those caring for a parent with a mental illness.

To order a Young Carers pack, contact the Commonwealth Carer Resource Centre in your state or territory on the national freecall number 1800 242 636. For more information, see [www.youngcarers.net.au](http://www.youngcarers.net.au) and the Carers Australia website [www.carersaustralia.com.au](http://www.carersaustralia.com.au).

### Siblings Australia

Siblings Australia (based in South Australia) works to increase awareness amongst parents, siblings and service providers, of the concerns of siblings of children with special needs; increase the provision of services to families and, in particular, siblings; improve networking opportunities for families and siblings to support each other; increase the opportunities for service providers to network and share/improve their skills in supporting siblings; and to enhance the inclusion of sibling support as part of 'core business' of relevant organisations. For more information see the website [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au).

[www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)



AAFCD Co-ordinator Helen Johnson (right) with the Executive Director of Carers Victoria Maria Bohan, discussing the latest 'Young Carers' initiatives of Carers Australia and state/territory Carers Associations.

### Your Shout Website

Your Shout is a website designed by, and for, adolescent siblings in Victoria, and is an initiative of the Association for Children with a Disability. Much of the site content is relevant to adolescent siblings in other states and territories and indeed, while designed for siblings, many parents have learned much about sibling perspectives by having a look at the site. See [www.yourshout.org.au](http://www.yourshout.org.au).



[www.yourshout.org.au](http://www.yourshout.org.au)



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