

# National NoticeBoard

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

## Keeping Our Heads Above Water

We have a 14-year-old daughter who was diagnosed with tuberous sclerosis and epilepsy at 12 months of age. She has also developed autism spectrum disorder and challenging behaviour. I also have a younger son who is nine years old and he keeps me sane. My little man has had to grow up fast and he is such a delight to have around.

When Sarah was six years old she ended up at the Royal Children's Hospital (RCH) with a twisted bowel which required immediate surgery. Sarah is now on lifetime medication and is prone to constipation.

Her medication is administered four times a day via syringe and the side effects make her dribble immensely. One of the medications gives her a false appetite while another medication makes her over eat, which means she is looking for food every two hours and drinks up to a litre of water given the chance at each sitting.

Sarah has an intellectual disability and no speech. She requires 24-hour care and is incontinent, however we are toilet timing her and having to take her every half hour.

Sarah's continence products cost approximately \$7,000 a year and \$450 is the only assistance we get each financial year.

My husband works full-time and he is on call 24/7 every two weeks out of a month and he is hardly home. I work part-time in between school hours, pending school holidays if I can get care. The local council only provides six hours a fortnight and other government funded services only provide us with 24 hours per financial year of care.

How are families supposed to keep their heads above water to make ends meet?

Our day starts before dawn, with Sarah being active for at least 16 hours a day. She is quite mobile and needs assistance with feeding, bathing, dressing and toileting. Sarah gets quite distressed if left alone (even for a quick trip to the toilet).

Having a child with a disability is exhausting and challenging to your health, marriage and

relationships. We have no family support. Relatives have said that Sarah's needs are higher than they can deal with. You certainly find out who your friends are, and the same goes for my son.

How can the government justify compromising the sanity of parents who want to keep their kids at home, by not giving them decent financial assistance?

It would certainly cost the government more if each family with a child who had a disability relinquished them and they had to provide funding for 24-hour care, housing and continence products.

We aren't asking for all of our continence costs funded but at least more than \$450 a year.

Frustrated Parent, Vic

### Continence Costs Advocacy

In addition to providing free access to the best available advice on toilet training and continence management, AAFCD believes that all government sponsored continence assistance schemes (including the Australian Government's CAAS Scheme for those aged 16 to 65 and state/territory schemes for children under 16) should include the capacity to provide up to \$1,500 per year of assistance for all continence needs.

The current maximum subsidy of \$470 (CAAS) and \$450 (subsidy allocation from the Victorian Government's Disability Continence Program) are ridiculously low for families with children with high support needs who use disposable continence products.

For more information and to contribute your experiences and suggestions on continence issues, see page 2.

Edition 21

September 2005

Print Post Approved  
PP352380/00006



The Hon Julie Bishop MP,  
Federal Minister for Ageing

The Continence Aids Assistance Scheme (CAAS) for people aged 16 to 65 is within Minister Bishop's portfolio responsibilities through the Department of Health and Ageing. State and territory governments are responsible for continence assistance schemes for children under 16 years of age.

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**AAFCD**

Australian Association for  
Families of Children with Disability

# Continence Assistance



AAFCD Co-ordinator, Helen Johnson and family

In the lead up to the next federal budget (and state/territory budgets) AAFCD will be putting forward the case for urgent and necessary improvements to continence assistance schemes across Australia. Our lobbying process will focus on families of children and young adults with high support needs.

While it's important to ensure that all families have access to the best available information about toilet training and continence strategies, governments need to recognise that many families with children with profound and severe disabilities have no other option than to spend thousands of dollars per year on continence products. This needs to be recognised within the structure of all continence assistance schemes.

Having one (low) level of maximum subsidy to cover all children, irrespective of the level of support needs, discriminates against families of children with high support needs.

The current maximum subsidy provided through the Australian Government's Continence Aids Assistance Scheme (CAAS) for people aged 16 to 65 should be immediately raised from \$470 to \$1,500 per year. The equivalent maximum subsidy for disposable continence products in state government schemes for children and young adults aged under 16 (eg. Victoria's Disability Continence Program) should also be immediately raised from \$450 to \$1,500 per year.

We recognise that not all families will require the full \$1,500 subsidy. We also recognise that many families spend much more than \$1,500 on continence products.

For families with children with high support needs, \$1,500 would be a lot more helpful and realistic than \$470, and we strongly believe it is a policy that governments can be convinced to implement.

In addition to the maximum subsidy levels, we will also be putting the case for other enhancements to continence information and assistance schemes.

It's important that all the latest information about continence management—such as that which I learnt from attending the recent national conference hosted by the Paediatric Continence Association of Australia (PCAA)—is made readily available to parents across Australia.

As always, the most powerful force in our lobbying efforts is the direct experience of parents and families. If you would like to contribute your experiences and suggestions about continence issues and the improvements needed to continence assistance schemes, please don't hesitate to contact me and have your say.

In every state and territory, we always need new parents who are prepared to 'tell it like it is' to help convince politicians and other government decision-makers about how their policies do (or don't) work in the real world for our families.

Helen Johnson, AAFCD Co-ordinator

## Continence Issues: Your Story

Have you got a story to tell about continence issues? Do you have experiences or opinions about how government continence assistance schemes should be improved?

State/territory government continence schemes for children with a disability aged under 16 vary considerably. If we were to rank these schemes from best to worst, where would your state/territory be on the list? Have you got the time and energy to be involved in the lobbying process to convince governments to make improvements? If you answered yes to any of these questions, I'd love to hear from you. Helen Johnson, AAFCD Co-ordinator, 1800 222 660, [helenj@aafcd.org.au](mailto:helenj@aafcd.org.au).

## Continence Information

For more information about continence issues, including links to continence aids and assistance schemes in your state/territory for children under 16 contact:

The National Continence Helpline,  
Continence Foundation of Australia  
Phone: 1800 33 00 66  
[www.continence.org.au](http://www.continence.org.au)

Paediatric Continence Association of  
Australia (PCAA)  
Phone: 03 9738 8585  
[www.pcaa.org.au](http://www.pcaa.org.au)

For information about the Continence Aids Assistance Scheme (CAAS) for young adults aged 16 and over contact:

The Health Care section of In Touch  
(A Division of PQ Lifestyle Ltd)  
Phone: 1300 366 455  
[www.intouchdirect.com.au](http://www.intouchdirect.com.au)

# Working Together

In addition to our Association, there are a range of groups and organisations across Australia who advocate to government and the broader community on behalf of people with a disability and parents/carers and families.

These include a range of nationally based disability advocacy groups and a network of state/territory based Carers Associations and Carers Australia (see below).

On issues of mutual concern, our Association seeks to work in co-operation with these groups. We see ourselves 'adding value' to their work by providing perspectives from parents of children and young adults with a disability.

If you haven't already done so, we'd encourage you to make contact with the

Carers Association in your state/territory. You might also like to contact any relevant national disability specific groups to explore what services they offer and to find out about any of their advocacy work that might be of relevance to families of children and young adults with a disability.

It's important to make sure that the voice of parents of children with a disability is heard within these organisations and more broadly within other community networks.

Helen Johnson, AAFCD Co-ordinator

## National Advocacy Groups

Australian Federation of Disability Organisations (AFDO)  
Phone: 03 9662 3324  
[www.afdo.org.au](http://www.afdo.org.au)

Australian Association of the Deaf (AAD)  
Phone: 07 3357 8266  
[www.aad.org.au](http://www.aad.org.au)

Australian Mental Health Consumer Network  
Phone: 07 3844 300  
[www.amhcn.com.au](http://www.amhcn.com.au)

Blind Citizens Australia (BCA)  
Phone: 03 9372 6400 or 1800 033 660  
[www.bca.org.au](http://www.bca.org.au)

Brian Injury Australia (BIA)  
Phone: 03 9482 9255  
[www.braininjuryaustralia.com.au](http://www.braininjuryaustralia.com.au)

Deafness Forum  
Phone: 02 6262 7808  
[www.deafnessforum.org.au](http://www.deafnessforum.org.au)

National Association of People Living with HIV Aids (NAPWA)  
Phone: 02 9557 8825 or 1800 259 666

National Council on Intellectual Disability (NCID)  
Phone: 02 6296 4400  
[www.ncid.org.au](http://www.ncid.org.au)

National Ethnic Disability Alliance (NEDA)  
Phone: 02 9687 8933  
[www.neda.org.au](http://www.neda.org.au)

Physical Disability Council of Australia (PDCA)  
Phone: 07 3267 1057  
[www.pdca.org.au](http://www.pdca.org.au)

Women with Disabilities Australia (WWDA)  
Phone: 03 6244 8288  
[www.wwda.org.au](http://www.wwda.org.au)

## Carers Associations

Carers Australia  
Phone: 02 6122 9900  
[www.carersaustralia.org.au](http://www.carersaustralia.org.au)

Carers ACT  
Phone: 02 6296 9950  
[www.carersact.asn.au](http://www.carersact.asn.au)

Carers NSW  
Phone: 02 9280 4744  
[www.carersnsw.asn.au](http://www.carersnsw.asn.au)

NT Carers Association  
Phone: 08 8948 4877  
[www.ntcarers.asn.au](http://www.ntcarers.asn.au)

Carers Queensland  
Phone: 07 3843 1401  
[www.carersqld.asn.au](http://www.carersqld.asn.au)

Carers Association of SA  
Phone: 08 8271 6288  
[www.carers-sa.asn.au](http://www.carers-sa.asn.au)

Carers Tasmania  
Phone: 03 6231 5507  
[www.carerstas.org](http://www.carerstas.org)

Carers Victoria  
Phone: 9396 9500  
[www.carersvic.org.au](http://www.carersvic.org.au)

Carers WA  
Phone: 08 9444 5922  
[www.carerswa.asn.au](http://www.carerswa.asn.au)

## National Carers Counselling Program

At various stages in our lives as parents of children with a disability, we might find it beneficial to have an opportunity to talk about our situation with a professional counsellor.

The National Carers Counselling Program (NCCP) is designed to provide short-term counselling and related emotional and psychological support services for carers.

NCCP can provide up to six sessions of counselling, free of charge. The program is administered by state and territory Carers Associations, in conjunction with Carers Australia.

For more information, contact your state/territory Commonwealth Carer Resource Centre 1800 242 636.

## Commonwealth Carer Resource Centres

Carer Associations in each state/territory run a Carer Resource Centre that provides a range of information relevant to all types of carers, including parents of children with a disability. All state/territory Commonwealth Carer Resource Centres can be contacted via the freecall number 1800 242 636.



## 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.



The Hon Brendan Nelson MP,  
Federal Minister for Education,  
Science and Training

### Best Buddies Program

Minister Nelson recently announced a \$100,000 boost for the Best Buddies program which facilitates opportunities for people with intellectual disabilities to explore new friendships and widen their social circles.

For more information about the Best Buddies program see [www.bestbuddies.org.au](http://www.bestbuddies.org.au).

In NSW, contact the New South Wales Council for Intellectual Disability on 02 9211 1611 or 1800 424 065. In Victoria, contact Big Brothers Big Sisters on 03 9427 7611. For inquiries in other states/territories, email [andrew.lloyd@bestbuddies.org.au](mailto:andrew.lloyd@bestbuddies.org.au).

### Disability Standards for Education

After 10 years of background work, the Australian Parliament recently adopted an official set of Disability Standards for Education. The primary purpose of the Standards is to clarify, and make more explicit, the obligations of education and training service providers (including schools) under the Disability Discrimination Act 1992 (the DDA) and the rights of people with disabilities in relation to education and training.

The Standards are based on the position that all students, including students with disabilities, should be treated with dignity and enjoy the benefits of education and training in an educationally supportive environment that values and encourages participation by all students.

To achieve this, the Standards aim to give students with disabilities the right to education and training opportunities on the same basis as students without disabilities. This includes the right to comparable access, services and facilities, and the right to participate in education and training unimpeded by discrimination.

Documentation related to the Standards can be found on the Federal Attorney General website ([www.ag.gov.au](http://www.ag.gov.au)) or by contacting the Department of Education, Training and Science on 02 6240 7562.

For more information about the DDA and disability discrimination, contact the Human Rights and Equal Opportunity Commission (HREOC) on 1300 369 711 or see [www.hreoc.gov.au](http://www.hreoc.gov.au) or your state/territory HREOC affiliated office.

### HREOC State/Territory Contacts

Australian Capital Territory  
Human Rights Office  
Phone: 02 6207 0576

New South Wales  
HREOC  
Phone: 02 9268 5555 or 1800 670 812

Northern Territory  
Anti-Discrimination Commission  
Phone: 08 8999 1444 or 1800 813 846

Queensland  
Anti-Discrimination Commission  
Phone: 07 3247 0900 or 1300 130 670

South Australia  
Equal Opportunity Commission  
Phone 08 8207 1977 or 1800 188 163

Tasmania  
Tasmanian Office of the Anti-Discrimination  
Commissioner  
Phone: 03 6223 4841 or 1300 305 062

Victoria  
Equal Opportunity Commission  
Phone: 03 9281 7111 or 1800 134 142

Western Australia  
Equal Opportunity Commission  
Phone: 08 9216 3900 or 1800 198 149

### AAFCD Funding and the Future

AAFCD began just over three years ago and already our membership has grown to 5,000+, and rising! In the next few months, we face some critical decisions about our future. We currently do not have a guaranteed source of income for AAFCD for the next year and beyond. We hope there will be some positive developments to report in November National NoticeBoard, so stay tuned!



Australian Association for  
Families of Children with Disability

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