

National NoticeBoard

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

A Marathon

"Family life with a child with a disability is a marathon rather than a sprint. A crucial aspect of supporting our families during the early years is to empower us with coping strategies that can help us 'run the full course' with our children."

The above piece of wisdom, from a parent in New South Wales, was the first of many helpful responses to the Remember When article in the last edition of National NoticeBoard (November 2005, Edition 22).

Thanks to everyone who read and commented on the draft of our new national booklet, *Helping You and Your Family: Self-help strategies and information links for parents of children with a disability*.

Your comments have been really helpful. Over the next few months, we will be refining the text and talking to government and other potential funders about the booklet's publication and distribution.

It is targeted towards new parents of children with a disability in the first few years during and after the identification or diagnosis of disability. It includes sections on: The Rollercoaster of Emotions; Family and Friends; Siblings; Looking After Yourself; Your Support Network; Parent/Professional Partnerships; and Information Links.

I was very heartened to receive the following feedback from a well known parent in South Australia who provided a perspective from her four decades of experience as a parent:

"This is brilliant! There was nothing like this available when our journey began in 1965. As a mum with 40 years' experience of supporting my daughter who has profound, severe and multiple disabilities, I can only reflect on what was NOT available to our family in 1965. For those of you who think that not a lot happens as far as supports and services for our sons and daughters, those of us who have been around for a while would disagree. But much more needs to happen! Unfortunately, it will only happen if you make it happen. Daunting? I agree, but when you

witness the result of your advocacy on behalf of your daughter, son, your family and yourself, it will be an indicator of JUST HOW POWERFUL YOU CAN BE!"

When you consider parents across all areas of Australia, and all types of disabilities, we are a pretty amazing bunch of people! And there are so many of us, too.

This time last year, in National NoticeBoard we published *Disability Counts* data for children and young adults with a disability in every state and territory (January 2005, Edition 17). Just looking at families of children aged 0–24 years with a profound or severe disability, there are more than 230,000 of us across Australia. When you include children with mild and moderate disabilities, the figure is 360,000+.

The Victorian Government is hoping to fill the MCG with 100,000 people to watch the opening and closing ceremonies of the 2006 Commonwealth Games. It's interesting to think that our families across Australia could fill the MCG three-and-a-half times over.

When we join together, share information and support each other, we are a strong force that can make a difference for the parents of today, and the parents of the future.

Helen Johnson, AAFCD Co-ordinator

Helping You and Your Family Draft

If you would like to read the latest draft of our new national booklet *Helping You and Your Family: Self-help strategies and information links for parents of children with a disability*, contact us by email mail@aafcd.org.au or 1800 222 660 (freecall from anywhere in Australia). As in all areas of our work for parents and families, your feedback is valued and important.

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The Hon Mal Brough MP

In the recent reshuffle of ministerial responsibilities announced by Prime Minister Howard, the Hon Mal Brough MP from Queensland was promoted to Minister for Families, Community Services and Indigenous Affairs.

Minister Brough replaces the previous Minister for Family and Community Services (FACS) Senator Patterson, with Indigenous Affairs also being added to the FACS portfolio.

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Australian Association for
Families of Children with Disability

The Voice of Families

One of the aims of AAFCD is to add strength to the voice of families of children with a disability in the media and political decision-making processes.



Helen Johnson, AAFCD Co-ordinator, and family

Contact Helen by email helenj@aafcd.org.au or on 1800 222 660 (freecall from anywhere in Australia).

Donations and Sponsors?

We're on the lookout for donations and sponsorship to be able to expand National NoticeBoard and make room for publishing more parent stories and other news and information updates from around the country.

If you have any ideas or contacts that might help us cover the costs of National NoticeBoard in the future, please let us know. Our membership/distribution is now 6,000+ and growing every month.

Apart from the worthiness of our cause, we would also represent great value for money for corporate sponsors.

Last year, I was contacted by a range of parents who were active in highlighting issues for their families in the media, including local papers, national current affairs TV programs and various magazines such as *Woman's Day* and *New Idea*.

Generally, the media is interested in the issues we face. I think it is great when parents have the energy to be out there 'telling it like it is' and providing a real-life perspective for the media to report on.

Every story in the media helps to educate the general community, and of course, political and government decision-makers are also keen consumers of all forms of media.

High profile media attention is not for everybody, but for those of you who have ever considered the potential value of the media to highlight issues for your family (and/or for other families in similar situations) feel free to give me a ring to discuss the possibilities.

Not all media coverage has to be focussed on our problems. Some media are also very interested in success stories about our children's achievements.

One really important part of the media is local papers. You would be amazed how many people actually read their local paper, including politicians who always read theirs very closely!

When I first looked at the *Disability Counts* data and discovered how many of us there are across Australia (see page 1), it got me thinking about the fact that every one of our families is unique. No two stories are exactly the same.

When it comes to media coverage, my dream is for the media to report on the full range of our experiences, across all ages and types of disabilities—the struggles, the success stories, and everything in-between.

Helen Johnson, AAFCD Co-ordinator

Governments and families

Along with a range of other national and state/territory organisations representing families of children with a disability, we are active in seeking to have family experiences and views heard as part of the decision-making process of governments.

While government decision-makers don't always like what we have to say—sometimes the reality of life for families seems a bit uncomfortable for department staff and politicians to hear—generally there is a preparedness to listen to the voices of parents speaking about real and recent experiences.

These days, across most areas of the federal government, AAFCD is well known and routinely invited to provide a parent perspective for any major policy reviews or consultations.

We are also never shy to make a direct representation to the relevant minister if we feel the bureaucracy hasn't really listened or heard our concerns.

For example, a big issue in the next few months is to make sure that no parent of a child with a disability is unfairly treated as part of the new measures in the government's Welfare to Work changes due for implementation in July. (See page 4.)

As part of the Welfare to Work agenda, the government needs to provide genuine and comprehensive support to parents of children with a disability who want to re-enter the paid workforce. This needs to include decent access to all forms of child care, including before and after school and vacation care, at an affordable price.

Michael Gourlay, CEO,
Association for Children with a Disability

Who's Who in the Government

In communicating with the Australian Government about the needs of families of children with a disability, there are a range of important portfolios/departments and Ministers. The hierarchy of ministerial responsibilities include the Cabinet, the Outer Ministry and Parliamentary Secretaries. In addition to the ministers responsible for employment issues and the government's Welfare to Work agenda (see page 4), key members of the government for families of children with a disability include:

Cabinet Ministers



The Hon Mal Brough MP
Minister for Families, Community Services and Indigenous Affairs

Member for: Longman (Qld)
Party: Liberal Party of Australia
Phone: 02 6277 7560
Email: Mal.Brough.MP@aph.gov.au



The Hon Julie Bishop MP
Minister for Education, Science and Training; Minister assisting the Prime Minister for Women's Issues

Member for: Curtin (WA)
Party: Liberal Party of Australia
Phone: 02 6277 7460
Email: Julie.Bishop.MP@aph.gov.au



The Hon Tony Abbott MP
Minister for Health and Ageing

Member for: Warringah (NSW)
Party: Liberal Party of Australia
Phone: 02 6277 7220
Email: Tony.Abbott.MP@aph.gov.au

The 'Outer Ministry' (ie. Ministers who aren't in Cabinet):



The Hon John Cobb MP
Minister for Community Services

Member for: Parkes (NSW)
Party: Nationals
Phone: 02 6277 7900
Email: John.Cobb.MP@aph.gov.au



The Hon Joe Hockey MP
Minister for Human Services

Member for: North Sydney (NSW)
Party: Liberal Party of Australia
Phone: 02 6277 7200
Email: J.Hockey.MP@aph.gov.au



Senator The Hon Santo Santoro
Minister for Ageing

Senator for: Queensland
Party: Liberal Party of Australia
Phone: 02 6277 5819
Email: senator.santoro@aph.gov.au

Parliament House

If you ever feel inspired to write to a minister or parliamentary secretary, the postal address is:

Parliament House
Canberra ACT 2600
Phone (02) 6277 7111
www.aph.gov.au

Department websites

www.facs.gov.au
www.dest.gov.au
www.health.gov.au
www.humanservices.gov.au

These, and other Australian Government sites, can be found through www.australia.gov.au.

Parliamentary Secretaries



The Hon Pat Farmer MP
Parliamentary Secretary to the Minister for Education, Science and Training

Member for: Macarthur (NSW)
Party: Liberal Party of Australia
Phone: 02 6277 2082
Email: Pat.Farmer.MP@aph.gov.au



The Hon Christopher Pyne MP
Parliamentary Secretary to the Minister for Health and Ageing

Member for: Sturt (SA)
Party: Liberal Party of Australia
Phone: 02 6277 4842
Email: C.Pyne.MP@aph.gov.au



AAFCD Membership— Spread the word!

If you are not already a AAFCD member, join up today! It's simple and FREE for families of children with a disability. Service providers, organisations and other concerned persons/community supporters are encouraged to subscribe to National NoticeBoard at an annual fee of \$15 (GST Inc) and/or make a donation.

If you know others who might be interested in AAFCD membership, you can spread the word by giving them a copy of our pamphlet and some back copies of National NoticeBoard (available free of charge on request to mail@aafcd.org.au or 1800 222 660).

Work/Family Balance

Via a major parliamentary inquiry, work/family balance will once again be a prominent issue on the political agenda in 2006. It's important that the views and experiences of parents of children with a disability are heard in the discussion of options for improvements to work/family policies.

If we don't speak up, there is a risk that these debates will proceed without an appropriate understanding of the fact that many families of children with a disability face significant additional work/family pressures that are directly related to their child's disability.

The work/family balance debate includes: child care access and cost; availability of part-time jobs; industrial relations and employer attitudes to family friendly working hours and conditions.

There are also significant links to the government's Welfare to Work agenda. This will include new measures to be introduced from July 2006 to encourage parents in receipt of some Centrelink payments to re-enter the workforce when their youngest child turns six.

One of the big issues for parents of children with a disability is the chronic lack of out-of-school hours care, including vacation care. How many employers are happy to hire people who need to take all school holidays off work? How many jobs are there for people who can only work during school hours? Not to mention parents needing time off when a child is too sick to go to school or has medical appointments during school hours.

Many parents of children with a disability would love to have increased opportunities to return to the paid workforce. But for many families this can only occur if there are

significant improvements to back-up support through flexible and affordable child care, including the capacity to support parents when children are too sick to go to school.

If you have something to say on these issues, I'd encourage you to write a letter or submission to the Work/Family Balance Inquiry. You might also like to write directly to the ministers responsible: Ministers Brough and Cobb for child care and vacation care, and Ministers Andrews and Stone about the realities of workforce participation for parents of children with a disability.

Michael Gourlay, CEO,
Association for Children with a Disability



The Hon Kevin Andrews MP
Minister for Employment and
Workplace Relations

Member for Menzies (Vic)
Party: Liberal Party of Australia
Phone: 02 6277 7320
Email: Kevin.Andrews.MP@aph.gov.au



The Hon Sharman Stone MP
Minister for Workplace Participation

Member for Murray (Vic)
Party: Liberal Party of Australia
Phone: 02 6277 7630
Email: S.Stone.MP@aph.gov.au

House of Representatives Standing Committee on Family and Human Services: Inquiry into Balancing Work and Family

Write to:

Mr James Catchpole
Committee Secretary
Standing Committee on Family and Human Services
House of Representatives
Parliament House
Canberra ACT 2600
Phone: 02 6277 4566
Email: fhs.reps@aph.gov.au
Web: www.aph.gov.au/house/committee/fhs

For more about the government's Welfare to Work agenda visit the Australian Government's Department of Employment and Workplace Relations website at www.dewr.gov.au or www.workplace.gov.au.



Australian Association for
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