



National NoticeBoard

Newsletter of the Australian Association for Families of Children with Disability

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Auspiced by the Association for Children with a Disability

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'Real life' Policy Advocacy

Well, whatever else you might have made of the Federal Budget, there was some good news about access to child care for children with a disability - an additional \$25.8 million over four years for the Special Needs Subsidy Scheme (SNSS).

Those of you who read the March 2003 edition of National NoticeBoard will know that we featured a family story and policy analysis of SNSS under the heading 'Child Care Freeze - National Disgrace'.

Over the past year, our Association together with other advocacy groups, the Federal Opposition and hundreds of individual parents and families have highlighted the negative impact of the freeze on SNSS funds and the need to boost the SNSS budget so that children with a disability can access child care.

In addition to advocacy through National NoticeBoard, our Association also directly lobbied key politicians in Canberra on the SNSS issue.

The formal SNSS Budget announcement noted that, "the extra funding will enable around 1,250 additional children and their families to access this highly successful program and will meet current demand for more SNSS places. SNSS nurtures children's development and supports families that want positive, developmentally appropriate environments and quality care for their children who have special needs. It is really important that these children can have the opportunity of being with other children, and take part in

the experiences that child care can provide".

Our own analysis of SNSS/Child Care Policy Solutions put the waiting list at around 1,120 and called for an extra \$5 million per year. The Government's response is to be applauded. Providing implementation is well planned and efficient, from July 1, 2003 we should see the SNSS waiting list reduce dramatically.

The SNSS initiative highlights what can be achieved when we work together with strong 'real-life' input from families combined with well researched and clearly documented policy solutions. Next up is Carer Payment (see page 3) and other Centrelink related financial issues. Education, via the new Education Standards, presents a major challenge for 2003/2004 (see page 2). Meanwhile, please keep us up-to-date with your ideas and suggestions for the big issues we should be tackling in Canberra and/or in your State/Territory.

Mary-Ann Murphy
AAFCD Committee Member, SA



Make sure you are on our mailing list to receive future editions of National NoticeBoard directly. See the Registration Form on page 4 or simply ring through your details on our free call number 1800 222 660.

Also, encourage others you know - parents and service providers - to join the mailing list and enjoy the benefits of National NoticeBoard. National NoticeBoard is a free publication.

Note: If you are on the SNSS waiting list, or would otherwise like to enquire about accessing child care (including all forms of child care such as vacation care) make contact as soon as possible with your child care service to ask about the implementation of this new money. If any difficulties arise, please contact us on 1800 222 660 and we can put you in contact with people in your State/Territory to help negotiate a solution.

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Quicknote:

The Committee of Management of our Association are all parents of children with a disability, including a wide variety of ages and types of disability. See back page for reps in each State/Territory.

The Australian Association for Families of Children with Disability (AAFCD) is auspiced by the Association for Children with a Disability. For updates and more information see www.acd.org.au

Your Story, Your Issues



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AAFCO Convenor

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Benalla, Victoria, 3672.

Those of you involved with our Association from the beginning in 2002 may remember the 'Top 3' issues form we asked you to complete.

The passion and feeling in your replies was fantastic. I have the original copy of every single response carefully filed in a folder in my office (and a very thick folder it is!). To the policy makers of the world - both bureaucrats and politicians - this type of information is gold, real examples of what 'real people' think.

In both its raw form (your quotes and your experience) and in a summarised form, we will continue to use this 'Top 3' issues input as our first line of argument when we advocate for policy improvements.

To add even more power to this policy and advocacy work, I'd like to update the 'Top 3' issues information by asking every parent/family member who hasn't yet done so, to contact me with their thoughts and experiences.

For those of you who did provide some input last year, if you have any additional thoughts, please let me know. It's easiest for

me if you email, fax or post your ideas in writing, but if you haven't got time to write, the phone is fine, although you might get an answering machine rather than me in person. Just leave a message and I will get back to you.

In case you need reminding, the question is:

If you had the Prime Minister, the Treasurer, the Minister for Family and Community Services and the Opposition Leader in your lounge room, and they wanted to know the 'Top 3' things the Federal Government could do to better assist your family and other families of children with a disability you know, you'd tell them...

1.
2.
3.

Please feel free not to restrict yourself to 3 things and write as much as you like about your experiences and suggestions. The more passionate the better!

Barbara Alexander AO
AAFCO Convenor



Back Copies of National NoticeBoard

Back copies of National NoticeBoard are available on the Internet - go to National Network on www.acd.org.au or contact the Association office on 1800 222 660.

Parent/Family Stories for Publication in National NoticeBoard

Parent/family stories are a popular feature of National NoticeBoard. See editions 1-6 for examples. Whether it's a story relevant to a particular policy issue (eg. SNSS in No. 6 or vehicle modifications in No. 5) a whole life story (eg. 'Hannah' in No. 4 and 'A Life Changing Experience' in No. 2) or about a particular event/phase or achievement (eg. 'Number One Eagle' in No. 1 and 'Our Holidays' in No. 3) there is inspiration in every parent/family story for other families, not to mention how much benefit the stories are in educating service providers and policy makers about real life!

Please don't be shy! If you've ever thought about writing your story but have never got around to it, now is the time. Ring and let us know in advance that you're doing it and I can let you know the deadlines for publication.

Education Standards

At the time of writing, Federal and State/Territory governments were in the process of analysing the 'cost/benefit' of introducing new Standards for Education as part of the Disability Discrimination Act. The process includes the usual sort of posturing between levels of government, with both arguing that each other should pay for the costs of implementing the Standards.

Federal and State governments constantly blaming each other is a very tiresome game. All we want is access to a decent education for our children, that shouldn't be too much to ask! See next National NoticeBoard for more background about the Education Standards debate including the likely impact 'on the ground' at the school level in 2004 and the lobbying we'll most likely need to do during the rest of 2003 to make sure we make the most of what the Standards have to offer.

Carer Payment - Profoundly Stingy!

In 1998, the Federal Government proudly announced that it was going to extend eligibility for Carer Payment (formerly known as the Carer's Pension) so that parents/carers of 'profoundly' disabled children aged under 16 would be eligible for the first time.

At the time, the background to the change sounded very positive - recognition of the fact that full-time employment is not a realistic option for many parents of children with a disability because of the demands of the caring role (and that part-time employment is often not an option either).

Unfortunately, something went terribly wrong between the announcement and the enacting of legislation to implement the change. In short, the Government adopted an absurdly narrow definition of profound disability the result of which is that certain types of children (those with intellectual and/or behavioural disabilities but without a physical disability or medical condition) have no chance of qualifying as 'profound'.

For example, Stephanie is a young girl with Autism featured in the Victorian Association for Children with a Disability video, 'Sharing Our Story: Parents of children with a disability talk about their lives'. I challenge anybody to tell me Stephanie is not 'profoundly' disabled, yet her parents would not qualify for Carer Payment on the basis that Stephanie would only meet one rather than the minimum three criteria required.

Did the Government really intend to be this narrow with the definition? If so, why? For anybody who has ever had to live on a Centrelink income, you'll know that one doesn't live it up! Carer Payment is no exception. If you had a choice between Carer Payment and working and earning the average wage, you wouldn't choose Carer Payment.

Was the Government seriously scared that thousands and thousands of parents of children with a disability would suddenly say, "You beauty, let's give up work and go on Carer Payment - we can live on \$20,000 a year less and have parties all day, every day looking after our child at home"?

Carer Payment for U/16's is either a bureaucratic stuff up or a shameful example of mean and stingy social policy. Either way, it should be fixed immediately. It would cost the Federal Budget a very small amount to extend Carer Payment eligibility to all the families of children with a disability who deserve it.

One of the barriers to change is that your average politician finds the issues around the definition all a bit too complicated. In the next few months we're going to go out of our way in Canberra to explain the reality in simple terms, using case examples of families. We remain confident that once 'the penny drops' and the powers that be understand the absurdity of the current definition in real, human terms, we'll get some action for change. The options include some simple solutions that will have the side benefit of savings in time and administration at Centrelink.

Christine Saunders,
AAFCO Committee Member QLD

'Sharing Our Story' is available for loan or purchase from the Victorian Association for Children with a Disability, phone 03 9500 1232.



Current 'profound' definition

To determine eligibility for Carer Payment for parents/carers of children under 16 years of age, the Government currently uses the following, absurdly narrow definition of 'profound' disability in Section 197 (2) (c) of the Social Security Act.

"the child's disability or condition includes 3 or more of the following circumstances:

(i) the child receives all food and fluids by nasogastric or percutaneous enterogastric tube;

(ii) the child has a tracheostomy;

(iii) the child must use a ventilator for at least 8 hours each day;

(iv) the child:

(A) has faecal incontinence day and night; and

(B) in under 3 years of age, is expected to have faecal incontinence day and night at the age of 3;

(v) the child:

(A) cannot stand without support; and

(B) if under 2 years of age, is expected to be unable to stand without support at the age of 2;

(vi) a medical practitioner has certified that the child has a terminal condition for which palliative care has replaced effective treatment;

(vii) the child:

(A) requires personal care on 2 or more occasions between 10 pm and 6 am each day; and

(B) if under 6 months of age, is expected to require care as described in sub-subparagraph (A) at the age of 6 months."

National Disability Advisory Council (NDAC) Nominations

NDAC provides the Federal Government with independent advice on matters relating to people with disabilities, their families, carers and service providers. We'd like to encourage parents to apply, NDAC needs an active parent/family voice. Contact Barbara at the National Association office for some background about NDAC.

Productivity Commission Inquiry into the DDA

It's not too late to make a submission or get involved in having your say. See www.pc.gov.au/inquiry/dda for details.

Centrelink/Financial Policy Suggestions

If you have any suggestions (or experiences you'd like to share) about Centrelink or other policies regarding financial issues for families of children with a disability, please contact with Barbara at the National Association office on 1800 222 660 or baraa1@iinet.net.au



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The AAFCD Committee members at a recent meeting in Adelaide, from left (back row) Cherie Shaw, Lyn Kemperman, Sue Griffin, Diane Fugslang, Clara Harris, Christine Saunders and Cheryl Patrick. Middle row (standing), Cheryl Shuttleworth, Barbara Alexander AO and Melinda Ewin. Front row (seated) Cale Dalton, Mary-Ann Murphy, Kylie Ramstadius and Bruce Young-Smith. Absent: Leonie McKnight, Jan De Witte and Karen Connaughton.

What is the AAFCD?

Our Association is a 'grass roots' organisation, run by parents/ families for parents/families. Our Association includes all types of disability. Our formally defined purpose is:

'To provide information, support and advocacy to families of children aged 25 and under with disability in all States and Territories of Australia. The advocacy role includes provision of information to the Federal Government about family needs and issues and advocacy for changes required to Federal policies and programs to address these needs and issues.'

AAFCD Committee Members

Australian Capital Territory

Karen Connaughton
Cheryl Patrick

New South Wales

Sue Griffin
Julie Brunsdon
Kylie Ramstadius

Northern Territory

Bruce Young-Smith

Queensland

Christine Saunders
Melinda Ewin
Leonie McKnight

South Australia

Mary-Ann Murphy
Cale Dalton

Tasmania

Cheryl Shuttleworth
Diane Fugslang

Victoria

Barbara Alexander AO
Jan De Witte
Lyn Kemperman

Western Australia

Clara Harris
Cherie Shaw

Contact Barbara Alexander AO on 1800 222 660 to be put in contact with your State/Territory rep.

Australian Association for Families of Children with Disability National NoticeBoard Membership/Subscription Form

If you're not already on our mailing list to receive National NoticeBoard, you need to register as a member/subscriber by sending in this completed form.

It's free for families and service providers.

I would like to be put on the (free) membership/subscription list for information from the Australian Association for Families of Children with Disability, including National NoticeBoard.

I am a: Parent/Carer A young person with a disability
 Service Provider Family friend/Concerned person Other

Name:

Organisation & Title:

Postal Address:

Town/Suburb: Postcode:

Phone: () Mobile:

E-mail:

(Optional) If parent/young person, child's name/your name, DOB and disability:

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Send this completed form to:

Australian Association for Families of Children with Disability
8 Grubissa Court, Benalla, Victoria, 3672 or Fax to (03) 5762 7000