



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

Vacation Care 'Catch 22'

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"David is 15 years old, 6 foot tall and 14 stone. He also has severe and multiple disabilities. My husband and I both work full-time. When my son was younger he regularly attended the school holiday program at the local Council near where I worked. After some hard work educating the program managers and staff about his care needs, the program worked brilliantly. We could rely on it for one week out of two every school holidays. We took it in turns to take the other week off and one week of the year we'd book him into respite and have the luxury of a holiday together. SNSS funding (the Special Needs Subsidy Scheme) was used to assist with extra staffing costs.

However as he reached secondary school age, the appropriateness of the program became an issue as most of the other children in the program were of primary school age (a six-foot tall 15-year-old together with mostly 5-10 year olds). I can see why some of the other parents were a bit concerned about him staying there.

When we shopped around for other school holiday options, we discovered there weren't any! When our kids get to secondary school, the whole vacation care system seems to just disappear. If anything, our needs increase when our kids get to be teenagers, yet the services, vacation care in particular, reduce dramatically.

Why does it have to be this way? Why does everything have to be so hard? All I want is for my teenager with a disability to have the same sort of access to vacation care as he had when he was younger, that shouldn't be too much to ask for!"



Kay Atlas with her son Tim (14) from the Sunday Age story 'Mother asserts son's rights to all-day care' (see page 2).

In policy terms, the problem of teenagers with a disability getting access to vacation care programs is something of a 'catch 22'. It is solvable, it just requires some understanding and commitment from the politicians and bureaucrats in charge of child care policy. The 'catch 22' goes something like this:

1. Mainstream vacation care programs (for all children) are designed for children of primary school age, usually up to age 12. For children without disabilities, the Federal funding to support these programs (namely, eligibility for Child Care Benefit (CCB) to help parents with the cost of care) is only available to children of primary school age.

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Budget Top 5

1. Carer Allowance
2. Carer Payment
3. Vehicle Modifications
4. Vacation Care for Teenagers
5. Promoting Family Self-Help Information, Support and Advocacy

See page 3 for more details.

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“Can you imagine the heartbreak of a mother of a child with a disability who is battling her way back into the workforce, in and amongst the demands of caring for her child with a disability (and other siblings), only to discover that with no access to vacation care, she faces another new hurdle on the road to secure employment. Life is hard enough for families of children with a disability without government red tape putting additional hurdles in the way.”

Excerpt from a recent letter on the Vacation Care issue we wrote to the Minister for Children and Youth Affairs, The Hon Larry Anthony, MP.

Your Story?

The parent/family stories are the most popular part of National NoticeBoard and we always need new stories. Send your story and a photo to The Editor, National NoticeBoard, Association for Children with a Disability, 590 Orrong Road, Armadale, Vic, 3143 or email (fionag@acd.org.au).

Vacation Care 'Catch 22' Continued...

2. For children with a disability, the age of eligibility for CCB for vacation care (and the SNSS Program) is able to be extended to 17.

3. Vacation care funding for children with a disability is only available to 'Commonwealth approved' programs and to achieve this approval, the programs must be based on an 'inclusive' model, ie. involving children with a disability along with other children.

4. However, children without disabilities aged 13–17 are not eligible for CCB for vacation care, therefore there are no inclusive programs for 13–17 year olds with a disability.

5. So, the eligibility of teenagers with a disability for CCB and SNSS for vacation care is a mirage — they might provide funding 'on paper' but the programs don't actually exist in the real world.

6. The only option is to try and have teenagers with a disability included in the mainstream inclusive primary school age programs. Sometimes this works, but, as in the example above, most of the time it is clearly not 'age appropriate' for both the teenager with the disability or the primary school age children without disabilities.

The solutions are quite simple:

- There should be new procedures introduced to expand the number and type of 'Commonwealth approved' vacation care programs for teenagers with a disability.
- This should include expanding the number of general, inclusive 'Commonwealth approved' programs for all teenagers and/or a special process for registering 'Commonwealth approval' for children with a disability within existing generalist and disability specific programs.

For example, currently, if a vacation care provider designed a program with six children with a disability aged 13–15 in together with another six children without disabilities aged 10–13, this would not be eligible for 'Commonwealth approval'. It would be against the rules. Common-sense tells us that this sort of program should be eligible, and that the process for determining Commonwealth approval should be flexible enough to accommodate it.

The necessary changes could, and should, be implemented quickly, within the context of the 2004 Budget. The actual cost to the budget would be minimal. In most instances there would be no increase in the cost to budget because the existing funding tagged to teenagers with a disability would simply be re-deployed from one program (the current age inappropriate all primary school age program) to a new age appropriate program, which in most cases would be run by the same provider.

The changed policy will free-up providers to offer more programs designed around the needs of teenagers with a disability. Therefore, some additional SNSS budget allocation for new vacation care places is required. We suggest a modest additional SNSS budget allocation of \$1 million which would include the capacity to undertake some pilot programs immediately.

The vacation care 'catch 22' is one of those policy issues that seems complicated, but is actually very simple (and cheap for the government to fix). Teenagers with a disability and their parents have a right to expect some positive action from government on this issue in 2004.

Media Coverage

The vacation care for teenagers issue featured in a recent article by Liz Gooch in the Victorian 'Sunday Age' newspaper (Feb 15, 2004, page 8) called 'Mother asserts son's right to all-day care'. The article featured Kay Atlas and her 14-year-old son, Tim (see photo on page 1). In the article, Kay, who runs a small business, said the authorities had 'no idea' about the stress placed on families of children with disabilities.

“He can't access other programs in his age group because there's none out there, that's where the problem lies,” she said.

Chief Executive of the Association for Children with a Disability, Michael Gourlay said, “In the lead-up to every school holiday period our switchboard is jammed with parents of teenagers with a disability desperate to find vacation care. Unfortunately, for most of these it's a fruitless search because the places aren't there.”

For a copy of the article ring us on 1800 222 660 or 1800 654 013.

Federal Election

A Federal election is due in 2004. The major parties are already in 'election-mode'.

Our approach to elections is to provide all major parties with access to information about 'real-life' family experiences and ideas about policy priorities. You can help by making sure your local Federal MP (and other candidates when they are announced) know about National NoticeBoard and our policy priorities.

You can ring and request additional copies of National NoticeBoard to put in the hands of your local MP. (We do post them all a copy, but it might take you visiting them in person to make sure they read and take notice of it.)

You might also like to consider requesting a formal meeting with your local MP to discuss your own situation (and that of other families you know). Often, politicians will not 'click-on' to the importance of a policy issue until they are confronted with a real-life example from within their electorate. You might also like to let them know a few facts about the potential size of 'the disability vote'.

The Disability Vote 6%+?

The facts include:

- When you have somebody with a serious disability in your family, their needs tend to dominate your way of living, your planning for everyday things like work, meal times, shopping, leisure time. Disability becomes your No. 1 issue.
- Disability ranks highly as an issue amongst friends and relatives of families of children and young people with a disability. These days, most people know someone with a disability they care deeply about within their family/friendship/workplace networks.
- ABS Stats show that over 6% of children have a serious life-long disability, that's 6 out of every 100 children in every electorate.
- When you factor in family, friends and other supporters within the general community, the number of people who would be disposed to cast their vote for a political party with clearly superior policy commitments to help people with a disability and their families — the disability vote — is much higher than 6%.

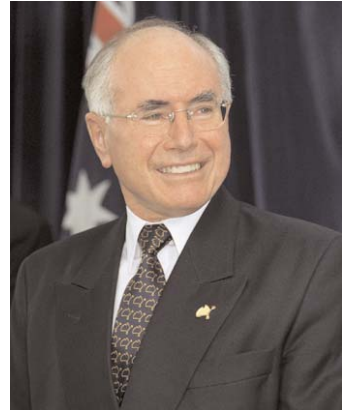
Federal Policy Priorities

Our Federal policy priorities include:

1. Carer Allowance rate of payment.
A \$20 pw rise from \$45.05 per week (\$2,342.60 per year) to \$65.05 per week (\$3,382.60 per year). See NNB Edition 11, Jan 04 for more details.
TOTAL COST: \$296 million per year across all ages (\$156 million for families of children/young adults aged 0-25)
2. Carer Payment eligibility rules.
Reforming the narrow definition of profound disability used for children under 16. See NNB Edition 7, May 03.
TOTAL COST: \$12 million per year
3. Vehicle Modifications.
New scheme to provide a 'base payment' of up to \$10,000 as a contribution to the cost of a modified vehicle. See NNB Edition 5, Jan 03.
TOTAL COST \$5 million per year
4. Vacation Care for teenagers.
Additional places and new programs. See NNB Edition 12, March 04.
TOTAL COST: \$1 million per year
5. Promoting Family Self-Help Information, Support and Advocacy.
Support to expand family self-help networks.
TOTAL COST: \$1 million per year
TOTAL: \$315 million

The focus of these priority areas is where the Federal government has clearly defined responsibilities for direct provision of support. Other areas of high need (eg. respite and education) have not been included at this stage as they are either defined as a State/Territory responsibility or a combined Federal/State/Territory responsibility.

To some, \$315 million might sound like a lot of money, but compared to the size of tax cuts provided last year (and further tax cuts likely to be promised again this year), it is quite a small amount. \$315 million represents about 60 cents per week per taxpayer (\$31.50 per year). Whatever size tax cuts the parties may have in mind, simply reducing it by 60 cents per week will ensure there is money to fund the above policy priorities for families of children with a disability.



Prime Minister, The Hon John Howard MP



Federal Leader of the Opposition, The Hon Mark Latham MP

Top 3 Policy Priorities Survey

Thanks to everyone who has submitted their 'Top 3' — 'Prime Minister and Leader of the Opposition in the lounge room' policy priorities. Your passionate contributions have been much appreciated and will be a powerful source of 'real-life' information for politicians and other decision-makers. A full report with a State/Territory breakdown of all responses will be released as part of our 2004 election lobbying.

If you haven't yet had your say, it's not too late. Give us a call on 1800 222 660 or 1800 654 013 or email Barbara in the national office (barbaraa1@inet.net.au).



Bruce Young-Smith, our Northern Territory AAFCO Committee member.

Bruce Young-Smith (NT)

Our daughter, Wendy, has cerebral palsy spastic quadriplegia. I never cease to be amazed by the courage of children with a disability to undertake the simple things most of us take for granted. As a rugby (both union and league) player/coach and martial arts instructor of many years I believe that I am qualified to talk on this. The sort of strength of character and frustration I talk about may be explained by the following experience.

I was following 5-year-old Wendy as she cruised hand over hand using her reduced grip around the edges of our small pool when a passing Harley Davidson out on the street decided to change down a cog or two and blast off. The resultant explosion of sound triggered Wendy's still strong infantile fright mechanism, which caused her to lose her tenuous grip on the edge of the pool and under the water she went. I was on the scene within a second but had to spend the next 25 minutes comforting her as she screamed with rage at herself for letting go of the pool edge. She still insists on being allowed to cruise the edge of the pool alone.

As my wife Buareon is Thai, and has only a reasonable command of English, I found that I needed to be at Wendy's examinations to help explain her history to doctors as well as to explain what they were saying to Buareon.

The equity I expected and took for granted on the footy field and in the sparring ring is still only a distant wish for those with a disability. I have resolved not to accept this and I continue to do what I can to try and set the scales right.

National NoticeBoard Direct

If you haven't already, please provide all the parents/families you know with information about National NoticeBoard and how easy it is to get on the membership/subscription list (see below) to have National NoticeBoard mailed directly to them at home.

What is the AAFCO?

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.'

AAFCO Committee Members

Australian Capital Territory

Karen Connaughton
Cheryl Pattrick

New South Wales

Sue Griffin
Kylie Ramstadius

Northern Territory

Bruce Young-Smith

Queensland

Christine Saunders
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 (or ring/email us with your details). 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:

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