



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

Votes in Disability!

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'Disability is important to me when I vote'
Postcard Campaign.
See pages 2-3.

There are votes in disability, heaps of them.

Estimates of the rates of disability amongst children and adults vary. The next edition of the 'Disability, Ageing and Carers' survey series from the Australian Bureau of Statistics (based on a new 2003 survey) is due for release on 28 June, 2004.

Data from the 1998 ABS survey says:

- 2.3% of children aged 5-14 have a profound disability
- A further 2.1% have a severe disability (giving a combined profound/severe rate of 4.4%)
- Another 2.2% have a mild/moderate disability

These profound, severe and mild/moderate totals add up to 6.6%. The 1998 ABS survey also included an 'All with disability' rate of 9.5% that includes an additional 2.9% of children with a disability whose disability wasn't 'specific' and therefore wasn't

included in the profound, severe, mild/moderate categories.

The rates of disability in the 1998 survey varied across States and Territories. For example, in Victoria, the combined profound/severe rate for 5-14 year olds was 3.4%, a full 1% below the national average. The Victorian total for profound, severe, mild and moderate was 6.0%, also well below the 6.6% national average.

With any attempts to define disability, there is always contention at the margins about where the line is drawn. I have heard some people suggest that the 1998 ABS Survey produced inflated/higher than the real rates of disability for the 5-14 year old group, particularly for the profound/severe category.

The new survey results will be interesting and should clear up debate about the 5-14 year old rate. I would not be surprised to see the national profound/severe rate fall back to somewhere under 4%. Continued on page four...

"At least 6% of children in Australia have a serious life-long disability, with at least 3% of those being 'profound/severe'."

"That's 6 out of 100 children in every electorate."

"But the disability vote is more than 6%" ...see pages 2-3

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The Australian Association for Families of Children with Disability is auspiced by the Association for Children with a Disability (www.acd.org.au).



Disability...when I vote

The 'Disability is important to me when I vote' Postcard Campaign is designed to demonstrate to local Members of Parliament (MPs) — both Federal and State/Territory — that 'the disability vote' is larger than they perhaps realise and does extend well beyond people and families personally affected by disability. The general taxpayer does care about children and young people with a disability and does expect government to use their taxes to provide a decent level of support to families.

Campaign Strategies

The campaign strategy assumes that every parent of a child or young person with a disability has at least five friends or extended family or colleagues/local community members who care deeply about the child/children/family enough for it to influence their vote; and that they will be willing to put themselves on the line and sign-up for the Postcard Campaign.

Campaign Success Depends on You

The success of the campaign depends on each and every parent/family actively recruiting and signing up at least five supporters (and making sure that the postcards are actually sent to the right local MPs). For people who can organise more than five, go for it!

When recruiting people for the Postcard Campaign, you may need to educate them about the reality of the (in)adequacy of the current support system. Some of our supporters in the general community have no idea how bad the situation is and they'll never know unless you tell them.

Politically Bi-partisan

The campaign is totally bi-partisan. It is aimed at all local MPs, irrespective of their Party affiliations. It is encouraging all local MPs to be more active within their Party to improve policies and funding for families of children and young people with a disability.

Timing — Federal and State/Territories

While this campaign is being launched prior to the 2004 Federal Election, its relevance is not restricted to the Election. We have planned for the campaign to be ongoing throughout 2004 and 2005 at both the Federal and State/Territory level. Ideally, each supporter would send two postcards — one to their local Federal MP and one to their local State/Territory MP.

Finding the right MP/Electorate name and address

If you, or any of your supporters, are not sure which electorate you are in, for your Federal electorate there is an easy way to search via the web site of the Australian Electoral Commission (AEC). Go to www.aec.gov.au and select 'Electorate Search'. Once you know your electorate and the name of your local member, you can find their contact details under 'Who Represents You', 'Representation', 'List of Members of House of Representatives'. You can also phone the AEC on 13 23 26 for this information.

Locating your local State/Territory MP is a bit trickier, but you can get there by following Internet links from the AEC web site to your State/Territory electoral commission and/or through your State/Territory's main government/parliamentary contact points which can usually be found either by ringing your State/Territory Parliament House or via their web site: www.vic.gov.au (Vic), www.sa.gov.au (SA), www.wa.gov.au (WA), www.nt.gov.au (NT), www.qld.gov.au (Qld), www.nsw.gov.au (NSW), www.act.gov.au (ACT).

If in doubt, ring us on either of our freecall numbers 1800 654 013 or 1800 222 660.

For more information

To obtain copies of the postcard, contact us on 1800 654 013 or 1800 222 660 or email a request to mail@aafcd.org.au or see our web site (www.aafcd.org.au).

If the cost of stamps is an issue for you, please contact us and we can help with costs. We know finances are a major issue for many thousands of families of children with a disability and we do not want any family to be further disadvantaged financially by participating in this campaign.

"Before it happened to me (having a child with a disability), I used to think that families of children with a disability got whatever they needed (from government funding and the service network).

I was totally shocked to discover the reality — I had no idea there would be long waiting lists for basic services and the extra costs involved in bringing up a child with a disability are way beyond what I imagined.

Sometimes I worry that the rest of the community thinks what I used to think. We have to educate people about the reality that government funding for services is inadequate.

I don't think enough people realise that families of children with a disability aren't getting the support they need."

Quote from a parent forum in Bayswater, Victoria, April 2004

Your Issues and \$20 pw

Thanks for the hundreds of passionate contributions to our 'Top 3 Policy Priorities' question and also 'What would you spend an extra \$20 pw on?' (if there was a \$20 pw rise in the Carer Allowance, January 2004 NNB). More contributions are welcome. We have and will continue to use your input to educate decision-makers about the reality of life for families.

"If I had an extra \$20 a week, I would use it on getting my son swimming lessons. Which would be very beneficial to him. It would help to strengthen his muscles and help his breathing as well."

"We are the parents of a child with a disability, who cannot walk and uses an electric wheelchair. We would use an extra \$20 pw to assist in repaying the \$60,000 required for a wheelchair converted vehicle for which we received almost no funding. Also, this would go partway to offset the fact that a second income is impossible for a family in our situation."

"Our son has a bladder and bowel problem. We are provided with \$450 worth of nappies per year, but this supply rarely lasts three months."

"How costly having a child with special needs can be. We pay \$300+ per month in speech therapy and physiotherapy as there aren't enough therapists available in the government provided services."

"I physically cannot lift my son in and out of our vehicle, so my husband must be with us, hence time off work. Public transport I'm told is the answer, but sorry, we live in the country."

"Twenty dollars pw would help to 'slightly' ease the financial burden of caring for a person with a disability: Things such as loss of income, clothing, specialist equipment, travel expenses. Every little bit of assistance is a small step in the right direction."

"Working and raising a family is hard enough, try it with a child with a disability. There are many appointments, illness, reduced attendance at school, all requiring you to drop everything. In my own experiences with employers, they either can't afford or aren't willing to give time off. This has left us with more financial pressures."

"I will never be able to work again while my child is at home and therefore will never have an adequate income."

"I would use \$20 pw to employ a carer for an extra hour a week to give myself and my family more break time."

"My husband works full-time and I am a stay-at-home mum, not by choice, but merely by circumstances. My daughter has Rett syndrome and is often not well, so I need to be available at all times."

"Having barely scratched the surface of 'extra costs involved with raising a child with a disability', I can see why families are exhausted. It doesn't even touch on the physical or emotional costs. There are costs that must be carried by the individual families, but the Australian Government can help us financially, and they must be made to realise that we love our children."

"Spend a day with my me and my grandson. He is my life, but I get so tired. He needs me for all his needs, so that's how it is."

Federal Budget/Election

This National NoticeBoard was prepared before the 2004 Federal Budget, but you're probably reading it after the Budget. Our Federal Policy Priorities for the election (see NNB Editions 11 and 12, January and March 2004) will be updated to take into account any budget announcements. See www.aafcd.org.au or contact us by phone or email for more details.

Your Story?

The parent/family stories are the most popular part of National NoticeBoard and we always need new stories. (We apologise for this edition being taken up totally by policy stuff and leaving no room for stories!)

Whether it's your whole life story — or just part of it — if you feel inspired to write, 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).

Your Local MP is there to help

Apart from needing to know who they are for the Postcard Campaign, we actively encourage all families of children with a disability to know, and use, their local MPs (both Federal and State/Territory).

They are your representative. They are there to help you.

If you are anything less than 100% satisfied with the level and quality of support you and your family receive, it's important that your local MP knows about it. Give them the opportunity to help solve any issues. They might just surprise you and be helpful!

In addition to the postcard, you might like to request a meeting with your local MP. Politicians will always tend to be more active in fighting for positive change if they have met 'real people' from their electorate who are directly affected by the issues/policies in question.

Active local MPs are often the key to getting positive policy changes.



from page one...

Based on the ABS survey and our own experience of providing information and support to families of children with a disability, when discussing disability policy with government decision-makers, we use a headline benchmark that 'at least 6% of children have a serious life-long disability, with at least 3% of those being profound/severe'. This is based on the most conservative analysis of the 1998 ABS survey, using the lowest State figure (Victoria) for the combined profound, severe, moderate and mild totals for 5-14 year olds.

Michael Gourlay,
CEO, Association for Children with a Disability



Updated disability data will become available soon with the results of the 2003 survey 'Disability, Ageing and Carers' due for publication by the Australian Bureau of Statistics on 28 June, 2004.

Note: The ABS recorded disability rates for children aged 0-4 are always much lower than for 5-14 year olds. (In the 1998 Survey, the national 0-4 profound/severe rate was 2.2%.) This is because for many disabilities, a clear diagnosis cannot be made when the child is aged 0-4. It is likely that the real rate of disability amongst children 0-4 is closer to the 5-14 year old rate.

In 1998, the profound/severe/moderate/mild rate for 15-24 year olds was 5.2%, with 2.0% profound/severe.

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.'

AAFCO Committee Members

Australian Capital Territory

Karen Connaughton
Cheryl Patrick

New South Wales

Sue Griffin
Kylie Ramstadus

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