



# 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 ~ ABN 39 835 407 788 ~ [www.acd.org.au](http://www.acd.org.au)

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## Taking Off!

Well, I am now two months into my role as AAFCD Co-ordinator, and while I'm constantly run off my feet with the long list of things to do, I am loving every minute of it. Thanks to everyone who contacted me after the last National NoticeBoard came out. Your passion and enthusiasm is much appreciated and our discussions continue to inspire me and give me more determination to continue to create awareness and advocate for positive change for our children in the future.

For those of you who receive the Victorian NoticeBoard magazine as well as National NoticeBoard, you will notice that November 2004 NoticeBoard includes a story from one of our AAFCD Committee members, Clara Harris, from Binu in WA, whose son has autism. Wouldn't it be great if every community responded to disability the way Binu has to Clara's son Sam?

There is plenty of goodwill in most communities when it comes to disability. One of our challenges is how to make the most of this goodwill, at the individual/family/community level and in broader community support for better government disability policies and funding. Please continue to send me your positive community stories.

Our AAFCD mission statement (see page 4) makes it clear that advocacy to government for better policies and funding is one of our key roles. We make no apologies for that! Creating better lives for our children and our families isn't just about what governments should do. Community attitudes in everyday life are also extremely important too!

In addition to the positive response from her extended family and her community, Clara's story highlights the positive impact of the inclusive attitudes of the children and teachers at Sam's school. Sometimes, the naturally generous attitude of young children can teach us adults a thing or two.

Much has changed in the world of disability over the past 20 years. I am confident the next generation are going to lead a much improved approach to supporting people with a disability and their families.

Meanwhile, we have the job of convincing today's politicians and the voting public that improvements are needed now! I cannot believe that amongst all the promises the federal government made in the election, they totally ignored the rate of payment of Carer Allowance which still remains at \$45.05 per week. If our children were cared for by the government in supported accommodation there would be a minimum cost of \$55,000 per annum! Families are saving the government and taxpayers billions of dollars every year. Surely we deserve more than \$45.05 per week?

So many families are struggling with increasing living costs while caring for their child with a disability. When will the government get their priorities right? We all love the environment but, why, in the last federal election, did the trees in Tasmania receive hundreds of millions of dollars and children with a disability and their families receive next to nothing?

Helen Johnson, AAFCD Co-ordinator



New AAFCD Co-ordinator, Helen Johnson with husband Peter, and sons Jayden and Ben.

### Information Kit Project

After a meeting with the Minister for Family and Community Services, Senator Kay Patterson earlier this year, we were successful in gaining a one-off grant of \$40,000 to develop a model for better provision of information to families of children with a disability.

For more information and to contribute your ideas to the Information Kit Project, contact Helen on 1800 222 660 or [helenj@aafcd.org.au](mailto:helenj@aafcd.org.au).

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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](http://www.acd.org.au)).*



# A Big Learning Curve

Our story starts in September 1995, which was also when I had just learnt that my father was dying of cancer. My husband and I decided to have another child and we found out I was pregnant, for the second time, just after my father died in February the following year.

It was a very hard pregnancy and I was sick the whole nine months. My blood pressure was unstable, blood tests and scans were never normal but further testing revealed nothing. Physically and emotionally I was wiped out. All I could do was get through one day at a time while caring for my other child, Zachary, a very bright two-year-old who we now know has an IQ of 149-plus (he is special in his own right!). I couldn't allow myself time to grieve over my father because I was already under enough pressure.

At one of my routine scans it was thought my baby could have Down syndrome. My baby never kicked or moved about. I was given the choice of having an amniocentesis but we had to decide in such a short time that we didn't go ahead. We thought 'what will be, will be' and that we would love our child regardless. After spending weeks in and out hospital because of my blood pressure, the day finally came (or rather my blood pressure was so dangerously high) that I was induced.

An hour-and-a-half later, our beautiful baby was born—just as my dad had said to my auntie all those months ago! We named him Denholm Kevin Roy (middle names after my dad).

My first question was, "Does he have Down syndrome?" There was no answer. I haemorrhaged badly and was given five bags of blood. It took me ages to recover, I thank my mother who looked after my newborn for the first three weeks.

About a month later, when Denholm was asleep one night, I noticed that his breathing was very laboured so I took him to the local hospital. He stayed there for the next week. We had follow-up appointments galore, with stays in the Brisbane Children's Hospital (a two hour trip each way).

Denholm never cried. He had to be woken up for feeds, which took an immense time. Trying to 'sit' a newborn while giving a bottle so he wouldn't choke and turn blue is tricky! We became quite clever in a very short time.



Denholm aged one-and-a-half (left), with his younger brother, Zachary

Denholm was a very floppy baby, like a rag doll in your arms, and delayed in all areas. When he was six weeks old he had an operation to see why he kept choking and gagging but everything appeared to be fine. In fact, all his tests and operations in the early days came back normal. But I knew something was amiss. It was terrible. My husband was caught between his mum saying nothing was wrong and me knowing something was wrong.

At four months, Denholm had no muscle control—his head rolled about, his limbs hung, still turning blue from feeding. I think they were some of the darkest days. The not knowing is the hard part, a roller-coaster of emotions.

Denholm started twice weekly therapy visits with a physio, OT and speech therapist—a round trip of about one-and-a-half hours, plus sessions. I tried to make them all on one day but sometimes this didn't work.

It was very exhausting, especially for Denholm. There is no question when it comes to your children that you do what you have to. My house was a shambles. Only the bare minimum was done. I had friends turn away because of the state of my house.

Ever so gradually, Denholm improved. At last, he could hold his head at the age of six months. Denholm continued to be assessed to find out why his eating and swallowing still wasn't good. He had pureed food at 12

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## Your story?

The parent/family stories are the most popular part of National NoticeBoard and we always need new stories.

If you feel inspired to write, please do! Send your story and a photo to Fiona Gullifer, The Editor, National NoticeBoard, AAFCD, 590 Orrong Road, Armadale, Vic, 3143 or email ([fionag@aafcd.org.au](mailto:fionag@aafcd.org.au)).

months until he was walking at three years of age. He was in and out of hospital for operations, grommets, his first eye operation and then his second.

He finally had a muscle biopsy and the results took three months to come back. They said it was Cylindrical Spiral Myopathy—a very rare muscle condition with extreme floppiness, global delay in all areas and a low IQ. Only a handful of people have this condition and that is why the results took ages to come back. Nobody knew the future for Denholm. It has been a big learning curve for everyone involved.

Today, Denholm is in Grade 3 at his Recommended Placement and his brother

attends another school. Denholm's appointments have eased up, except for the usual three or six month appointments with the paediatrician, eye specialists, neurologist, ear nose and throat specialist, orthopaedic surgeon (he has a curve in his spine), a urologist and of course therapy, which I get from the Cerebral Palsy League of Queensland. Fatigue is still a real concern and most days he has a sleep at school

During the last seven years I have met some wonderful people whom I would never have met if not for having a child with special needs.

Louise Willmer, Queensland

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“Only a handful of people have this condition and that is why the results took ages to come back. Nobody knew the future for Denholm. It has been a big learning curve for everyone involved.”

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## New ABS Disability Data

You may have read or heard it said that 20% of the Australian population (one in five) have a disability. The 20% headline figure is misleading and unhelpful when it comes to the debate about government funding and support for families of children and young adults with a disability.

While the 20% figure is true when referring to an 'all with disability' rate measured by the Australian Bureau of Statistics (ABS) for the entire population (including the aged) the rates of disability amongst children and young adults are much lower (see Table 1).

The ABS includes estimates of 'profound', 'severe', 'moderate' and 'mild' disability, as well as an 'all with disability' rate. For various reasons, which we haven't the space to detail here, the 'all with disability' rate is higher than the combined total of profound/severe and moderate/mild.

When we cite ABS statistics to focus community and government attention on the needs of families of children and young adults with a disability, we believe the most appropriate figures to use are those for

profound/severe and moderate/mild. For example, the Victorian Government has expressed concern that the number of children with a disability they are assisting with disability-related education funding has grown beyond 3%.

Program documentation clearly states the funding is targeted to those with a profound or severe disability. But at 3%, the government would only be assisting 61% of children aged 5–14 with a profound/severe disability and less than half (45%) if those with moderate/mild disabilities were included in the target group. We would say, based on the ABS data, until disability education funding exceeds 4.9% of the population, there is no problem and no need to tighten eligibility criteria or restrict funding.

Table 1: Children and Young People with a Disability in Australia—Proportion of population with a disability

Age	% with Profound or Severe Disability	% 'Moderate' or 'Mild' Disability	Total %	Estimated Total Number
0–4	2.9	0.1*	3.0	37,939
5–14	4.9	2.0	6.9	187,468
15–24	2.2	2.6	4.8	130,953
<b>TOTAL</b>	<b>3.4</b>	<b>1.9</b>	<b>5.3</b>	<b>356,360</b>

Source: Australian Bureau of Statistics, Disability, Ageing and Carers: Summary of Findings (2003 Survey) Table 2, page 16.

Notes: All figures are national. At the time of writing, specific figures for different states/territories were unavailable, but due for release soon. 'Estimated Total Number' derived by applying rates for profound/severe and moderate/mild to latest available general population figures for Australia (June 2003). \*Denotes figure is statistically unreliable.

## National NoticeBoard Mailed Direct!

### It's FREE for families.

If you received this National NoticeBoard mailed directly to you, it means you are on our membership/subscription mailing list. If you have received it from some other source, you need to officially sign up as a member/subscriber to make sure you don't miss out on future editions.

See the membership form on page 4 or ring 1800 222 660 for more information. We want all families and service providers to enjoy the benefits of getting National NoticeBoard direct.



Over 650 members of the autism community participated in 'An Audience with Autism'.

The Biennial Autism Conference was held in Canberra 1-3 October, with over 440 people attending. Delegates presented on a range of topics which can be viewed at <http://autismact.homemail.com.au>.

The Autism Council of Australia ([www.autismaus.com.au](http://www.autismaus.com.au)) and A4 ([www.a4.org.au](http://www.a4.org.au)) used the opportunity to meet and develop a formal Memorandum of Understanding on working together on shared objectives.

### A4 and other national disability organisations

The national autism spectrum disorder group A4 (Autism Aspergers Advocacy Australia) held their first national awareness event 'An Audience with Autism' on the lawns of Parliament House in Canberra on 30 September 2004, to coincide with the Biennial Autism Conference.

Over 600 chairs were lined up on the lawn, each representing a person with autism spectrum disorder. Each chair held a brief description or photograph of a person affected by autism spectrum disorder. Another group of chairs represented politicians who showed their support by sponsoring a chair. The chairs stood silently before Parliament House. People gathered near Old Parliament House then walked up the rise to the Audience with Autism, followed by speeches from a student with autism, politicians and Judy Brewer-Fischer.

The Audience with Autism event is a good example of how disability specific groups/organisations like A4 can become a powerful force in raising awareness of disability issues at a national level. We encourage families to join relevant disability specific organisations as well as being active members of AAFCO so that we can unite together and work on issues that reach across all disabilities.

### 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

Cheryl Patrick

##### New South Wales

Kylie Ramstadius

##### Northern Territory

Bruce Young-Smith

##### Queensland

Leonie McKnight

Gerardine Hoogland

##### South Australia

Cale Dalton

##### Tasmania

Diane Fugslang

##### Victoria

Barbara Alexander AO

Jan De Witte

##### Western Australia

Clara Harris

Contact Helen Johnson on 1800 222 660 to be put in contact with your state/territory representative.



## 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 this completed form to the address below or join online at [www.aafcd.org.au](http://www.aafcd.org.au). 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  
590 Orrong Road, Armadale, Victoria, 3143 or Fax to 1800 222 660