



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

Edition 1
May 2002

New beginnings



Barbara Alexander AO, with husband Rand and son Simon (now deceased)

Hello everyone, welcome to the first edition of National Noticeboard. My name is Barbara Alexander and I am ecstatic that the Association for Children with a Disability has agreed to auspice the new Australian Association for Families of Children with Disability, until the end of December 2002. You have heard of the window of opportunity - well, this is our chance to have our own national organisation which will provide a voice for all families of children with disability aged 0-25 all over Australia.

Just to let you know a little bit about me, I am a parent of two boys, Drew and Simon (both deceased) who had a degenerative condition called Cockayne Syndrome. They participated in everyday life as much as they could and as a family, we experienced all the issues you face every day - from early intervention to school, supported employment, accommodation and everything in between. I have been a member of many

committees, review panels and boards and know first hand, the value of effective and timely lobbying.

In March, active parents from all States and Territories met in Victoria to form the Australian Association for Families of Children with Disability. After getting to know each other, it became apparent that we all had issues in common that could only be addressed if we had a national network of families.

The purpose of our new Australian Association is to provide an avenue for parents and families of children with disability across Australia to share experiences, support each other and advocate for a better deal from governments at both the Federal and State/Territory level.

So now it is your turn. As parents of children with disability, you experience the real world, so we need you to register as a member, advise us what affects your family life and what issues you would like to see addressed. Tell us your story, warts and all, a real story about real people. We will then put the collective facts into a draft policy document, facts that key decision-makers will not be able to deny, because they are your stories.

Please contact us, either by phone, fax, email, send a letter or just fill out the membership and 'issues' form on the back of this newsletter. This is our chance, let's take it.

Barbara Alexander AO

Your Top 3 Policy Priorities!

See form on back page to contribute your Top 3 policy priorities.

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Quicknote:

This edition of National NoticeBoard was prepared before the Federal Budget due for release on May 14. For details, see www.acd.org.au

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

Number One Eagle

When I was pregnant with our fourth child, my husband, Tony, and I would often wonder if we would have a boy. We didn't hold high hopes because we already had three girls. When David was born, Tony held him up to his face and said, "He looks just like me!" I said that they looked like David and Goliath. We both agreed that his name would be David. It was fate, because at the time we didn't realise he would be a little David who would take on challenges of Goliath proportions.

When David was four months old, he was diagnosed with Cerebral Palsy. The paediatrician told me that David might never walk, talk or be able to do much at all. Our lives were shattered.

David went through physiotherapy, occupational therapy, and speech therapy. He also had a daily routine of stretches and massages at home.

When he was four, David started to show a huge interest in the West Coast Eagles (Aussie Rules) football club. He watched all the games on the television and learned all the players' names. I was so confused. I thought it was really sad that David loved footy, but would never be able to play. Then someone suggested to me that I take him to watch the Eagles train. This was a turning point in his life.

David would drag his K-walker across the lawn and get a good spot where he could hear what the coach was telling the players. Daily exercises that had always been met with an argument at home, were suddenly a breeze to achieve when we were watching the Eagles train. David would copy the Eagles while they did their stretches and he was making huge progress in all areas.

David took his first steps on Subiaco Oval. It was an incredible moment. David became a regular at training and I am sure the Eagles loved having him there. In fact, I am sure that he inspired them as much as they inspired him.

When David was six, he had major surgery which involved reconstructing both his legs. He was hospitalised for two weeks and couldn't weight-bear for eight weeks. He had to learn how to walk all over again. While he was in hospital, I asked him to set himself a goal that would be fun for him to do when he could walk again. He told me that all he had ever wanted to do was kick a footy.



Kerry and David with Eagles player David Wirrpunda
(Photo courtesy of 'Eagle Eye' magazine.)

After two years of rehabilitation and hard work, he was strong enough to kick a footy. We were on Subiaco Oval at training when two of the Eagles players, Adrian Barich and Michael Prior, helped him kick his first footy. It was such a weak little kick that shocked David so much that he fell backwards in delight! "Mum," he said, "did you see it? I kicked a footy!" to which I replied, "I saw it mate, it's the best kick I have ever seen!". I cried for two days and rang everyone I know telling them my son had kicked a footy.

David's relationship with the players grew more and more over the years. The Eagles have been there for David through all his milestones. The most amazing highlight of David's life came this year when he was asked if he would be the inaugural Number One junior ticket holder for the Eagles.

He was finally an Eagle. Just one of the boys. David told me that he was going to be an Eagle when he grew up. "David," I said in a caring voice, "You won't be able to play footy for the Eagles because you will never be strong enough". "Mum, you don't have to kick a footy to be in the team. I am going to be their manager!". That's my boy.

Kerry Naso
Inglewood, Western Australia

"David took his first steps on Subiaco Oval. It was an incredible moment. David became a regular at training and I am sure the Eagles loved having him there. In fact, I am sure that he inspired them as much as they inspired him."

"It was such a weak little kick that shocked David so much that he fell backwards in delight!
"Mum," he said, "did you see it? I kicked a footy!" "

Your story please!

In future editions of National NoticeBoard, we'd like to publish parent/family stories from all over Australia. It can be as long or as short as you like.

Send your story with a photo to Barbara Alexander, 8 Grubissa Court, Benalla, Victoria, 3672 or email barbaraa@cnl.com.au

About the Association...

What is the purpose of Australian Association for Families of Children with Disability?

The formally defined purpose of the Australian Association for Families of Children with Disability is:

"To provide information, support and advocacy for families of children aged under 25 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."

How long has the Association been going?

The Association officially began life on March 21, 2002 at a meeting in Melbourne with parent representatives from every State/Territory.

Are there any politics involved? What's the background story?

The Association is unashamedly political in that we aim to represent the interests of all families of children and young people with disability. Our job is to educate, hassle, cajole, whatever it takes for the government of the day (and the Opposition and minor parties) to adopt better policies and funding commitments to assist families of children with disability.

The initial drive to establish a national Association has come from parents involved with the Victorian based Association for Children with a Disability (ACD) a parent self-help group with a membership of 4,000+ which was established in 1980.

Consultation with parents from other states and territories over the past five years clearly indicated the enthusiasm for a national network was shared by parents across Australia. It was just a matter of finding a few resources and the right time to formally get started.

Is it true that membership is 'Parents-only'?

To be more precise, voting membership is for parents/families only. Professionals, organisations and government department staff are welcome to join the subscription list for National NoticeBoard and other information (see form on back page), but they are not eligible to become voting members of the Association. Our Association is a genuine, 'grass roots' organisation, run by parents/families for parents/families.

Are all types of disability covered?

Our Association includes all types of disability.

What is the Committee Structure?

Initially, the Association will operate under the legal auspice of the Association for Children with a Disability with a Committee of Management comprising of at least one (and up to three) parent members from each State and Territory in Australia. The current committee (see list this page) is drawn from parents who have expressed interest in the planning phase and/or who attended the Melbourne meeting in March 2002.

At a later date, the Association will become legally incorporated as a separate organisation, at which time on-going arrangements for electing State/Territory committee reps will need to be finalised as part of a formal constitution.



Cheryl and Steven Patrick (ACT)
with their son, Ben

Australian Association for Families of Children with Disability Committee Members

ACT

Cheryl Patrick
Karen Connaughton

Northern Territory

Bruce Young-Smith
2nd NT?

Tasmania

Cheryl Shuttleworth
Gail Smith

South Australia

Mary-Ann Murphy
Cale Dalton

Queensland

Melinda Ewin
Leonie McKnight

Victoria

Barbara Alexander AO
Lyn Kemperman
Jan De Witte

NSW

Lisa Brown
Julie Brunson

Western Australia

Clare Masolin
2nd WA?

To be put in contact with your State/Territory reps, phone Barbara on freecall 1800 222 660.



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Mailing List Registration Form and 'Top 3' Policy Priorities Input

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

'Top 3' Policy Priorities

If I had Prime Minister Howard, Peter Costello (Treasurer), Amanda Vanstone (Minister for Family and Community Services) and Simon Crean (Leader of the Opposition) in my lounge room and they wanted to know the 'top 3' things the Federal Government could do to better assist my family and other families of children with a disability, I'd tell them...

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3.
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Please feel free to add additional comments/priorities:

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Australian Association for Families of Children with Disability

Mailing List Registration Form

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

- 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:

Email:

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

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