



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 3

September 2002

Your Priority Issues

Welcome to the third edition of National NoticeBoard. Your response has been fantastic! We have written to Senator Amanda Vanstone, the Federal Minister for Family and Community Services, to arrange a meeting to discuss what you have told us. Our primary job as your national network is to lobby hard on your behalf to the Federal Government. With the information you have already given us - and please keep it coming - we can begin the lobbying process in earnest. As parents, you will not be surprised to hear the 'Top 3' priorities:

1. Respite
2. Education
3. Financial Issues and Centrelink

We all know about the lack of respite. As one family wrote, so succinctly, their three priority issues were, "1. Weekend Respite. 2. Respite. 3. More Respite." Another comment, from a rural family, was, "We have a lack of respite other than emergencies. Why are we made to feel so guilty?"

The issues raised around education were varied. The lack of support in mainstream schools was high on the list. Most parents thought teachers did a wonderful job with limited resources. Another issue was inadequate integration funding for children attending Catholic and independent schools.

The need for a substantial increase in the rate of Carers Allowance was also listed as a high priority. In the words of one



Barbara Alexander, Will (who featured in the video) and Ann Sherry (a Sydney based Westpac Executive who is also a parent of a child with a disability) at the Association for Children with a Disability (Vic) launch of 'Sharing Our Story'. See page 3.

family, "We need better recognition of the wonderful work parents and carers do and the sacrifices we make daily." Other key issues included aids and equipment, services for very young children with a disability and restricted access to child care and vacation care.

Many parents said they were tired of having to fight for every little thing. As summed up by one parent, "Once a child has been diagnosed with a permanent disability we should get ongoing support. Cut out the structures and layers. Give the money to us!"

Barbara Alexander AO

Your 'Top 3' Priorities

In preparation for a concerted lobbying campaign we will be compiling a full report of all your contributions, including all the best quotes and a list of specific policy suggestions.

Meanwhile, more contributions via the 'Top 3' Registration Form are most welcome. If you have already filled out a priority issues form, please pass any spare copies you have on to another parent.

Your views are important! For more information, phone me on 1800 222 660 or check our progress via www.acd.org.au

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Quicknote:

Some very active parents in New South Wales have just registered the Association for Children with a Disability NSW Inc. Good Luck to you all. If you wish to be put in touch with this new group please ring Barbara on 1800 222 660.

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

Our 'Holidays'

Firstly, I gave the title of this article a bit of thought. When you read it you will realise that what we do isn't a 'holiday', but it is a change of scene and we think that it's worth the effort, for our whole family.

My husband, Dock, and I have three daughters, Sally (16), Robyn (12) and Kate (9). Sally has Rett Syndrome. If any of you are familiar with this disability, you will know that it is profound and causes complications such as Epilepsy, Osteoporosis, failure to thrive, breathing problems, lack of purposeful hand function, lack of speech, and lack of mobility. Sally has all of these, but we try not to dwell on them too much.

As both Dock and I have been campers since B.C. (Before Children), it was natural for us to try to maintain a pastime that we love. We wanted to give this message to our children too. As Sally's disability became more complicated and she got older and heavier, camping has become (potentially) harder.

However, by being flexible and practical, we have managed to overcome most of the barriers that prevent people with disabilities from camping.

Firstly, we have a concertina-folding wheelchair as a 'traveller' for Sally. Dock, who is a bit of a bush welder, has rigged up a carrier on the back of our car where the tyre was, so that the wheelchair doesn't take up all the space inside the car and is easily accessible when we stop. A friend of ours made a vinyl cover for it to stop it getting wet and muddy.

When Sally went onto tube feeding (gastrostomy), I thought it would be the end of camping, but it was really the opposite. It is actually easy to keep her tubes clean using bottled water and a thermos, which means that we can go most places. It used to take hours to feed Sally orally, but now I can now jump in the back seat and tube feed her as we keep driving.

When Sally went to a pump to get more nutrients into her, I thought, this is it (again). We have an excellent dietician, who put Sally on a Micro-max pump that has a battery which lasts three nights without charging. As we sometimes go



Sally and Dock at a dry creek bed near Arkaroola

bush for longer, Dock got a charger that fits into the car cigarette lighter and we were in business again.

More often than not, it is during the colder months when we can get away. Soon after Sally went on the pump, we were camping one night and her alarm went off. This meant that there was a blockage with her feed. We worked out that the night air was too cold and the milk wouldn't flow through the tubes. We now take a hot water bottle and a foil wine bag to keep the feed warm. A simple idea, but it makes all the difference.

Sally's weight is also an issue. I think that soon we will need a car hoist, or a van. Thank goodness Dock is big and strong because it is really hard for me to lift Sal when we are away from home. As our other girls get older, they want to explore more. In some situations, we take it in turns to do the bush walks. Places like Wilson's Promontory and some desert country are very accessible. Sometimes both of us want to be the one that stays at camp to look after Sal (and get the chance to snooze and read).

So that's how we camp. It's not easy, but it's the only way that we can do it as a family and we all enjoy it. If you are thinking about camping with your kids, go for it!

Cathy Hair (Goorambat, Vic)

Your story?

We would love to hear from you! Send your story and a photo to Barbara Alexander, 8 Grubissa Court, Benalla, VIC, 3672.

"We recently travelled to Cameron's Corner, which is where NSW, Queensland and South Australia meet. Needless to say, it is very remote (even for us) but well worth the trip.

"Sally was particularly well, which made it easier. However, it was still fun to try and push the wheelchair through the sand up there!"



Rett Syndrome Association of Australia

The Rett Syndrome Association of Australia (RSAA) was established in 1989 in response to the needs of children with Rett Syndrome and their families.

The group aims to develop an understanding and awareness of the disorder and further the advancement of research, therapy and care.

For more information contact the RSAA on 0412 561 796

or write to:

The Secretary

Rett Syndrome Association of Australia Inc.

GPO Box 3497

Melbourne, Victoria 3001

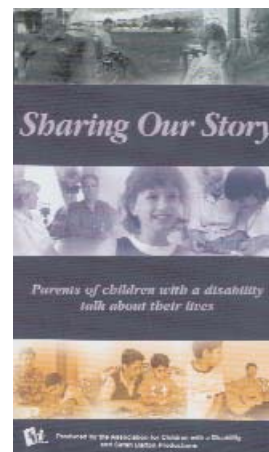
'Sharing Our Story'

The 'Sharing Our Story' video features 5 families of children with a disability from Victoria. It was made as a training tool for the full range of professionals and service providers involved in assisting families of children with a disability.

If you are involved in providing services or other assistance to children with a disability and their families, this video and the training workshops will inspire you to better understand the world from a family perspective and to improve the services you provide.

"Both my husband and myself try to maintain a positive, realistic attitude towards our children. But what really hurts is when other people, and sometimes these are service providers, give one of our children a label that comes with a set of instructions about what she can, can't and will do. I believe that every human being is unique and has something important to offer to humanity. And our children, who happen to have a disability, are no different."

Kathy Spowart, parent of Ally from 'Sharing Our Story'



'Sharing Our Story' video and training packages are now available. Contact the Association for Children with a Disability (Victoria) on (03) 9500 1232 or 1800 654 013.

Unfortunately, we don't have the financial resources to send a free copy of the video to every parent/family. Options to view the video include encouraging a service you use to purchase a copy of the video and training programs for their workers and to also make the video available on loan to parents.



Australian Association for Families of Children with Disability

Our Purpose

The formally defined purpose of the Australian Association for Families of Children with a Disability 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."

Membership

Voting membership is only available to parents/families of children with a disability. Professionals, organisations and government department staff are welcome to join the subscription list for National NoticeBoard and other information, but they are not eligible to become voting members. Our Association is a genuine, 'grass roots' organisation, run by parents/families for parents/families. Our Association includes all types of disability.

Attention all Rugby League, Union and Soccer Fans!

You are letting the team down! We have had a huge response from AFL fans to David Naso's story about the West Coast Eagles, which appeared in our first edition of National NoticeBoard. Do you have any good stories about people from your sport being encouraging and supportive of children with a disability? If not at the elite level, at junior or club levels? Do you have any other 'good news' stories about children with a disability participating in sport or recreation activities?

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

Special Needs Subsidy Scheme (SNSS)

Thanks for your response to the July National NoticeBoard regarding problems with access to child care and vacation care via the SNSS scheme. SNSS issues will feature prominently in our lobbying/policy work.

Deadline October 4th

We welcome your contribution to National NoticeBoard. Deadline for the final edition of the year (November) is October 4. Send to Barbara Alexander, 8 Grubissa Court, Benalla, 3672 or email barbaraa@cni.com.au



Back Copies of National NoticeBoard

Back copies of National NoticeBoard are available on the Internet via the Association for Children with a Disability (Victoria) web site www.acd.org.au or ring Barbara on 1800 222 660.



Lisa and Nathan Brown

Lisa Brown (NSW)

My name is Lisa Brown and my husband, Andrew, and I have two sons. Nathan is almost 4 and Mitchell is nearly 3 years old. Nathan was diagnosed with cerebral palsy at 6 months of age. Currently, I am assisting in getting an Association for Children with a Disability started in NSW. With the assistance of the Spastic Centre of NSW, I've also been involved in a monthly parent discussion group.

Having a child with a disability is hard work and it is annoying that the governments at both State and Federal levels have not recognised the fact that more financial resources are needed. I feel that the only way we will ever have equality for our children is if members of parliament had first hand experience with varying degrees of disabilities by visiting families who have a disabled family member and staying for at least two nights!



Cale and Neil Dalton

Cale Dalton (SA)

My son Neil is 21 years old and I share the care with my wife Dorothy. I contribute to the work of a range of organisations that assist or advocate for people with disabilities and their carers. This includes Parent Advocacy in South Australia. My special interests include improving opportunities for students with disabilities and encouraging parents/carers and people with disabilities to have a greater say in decisions or policies that affect their lives.

I'm really pleased to be able to contribute to the new Association. It has been extremely rewarding to link up with parents from all over Australia and discover how much we all have in common. While we may have separate battles to win with our State/Territory governments, it is nevertheless encouraging to find ourselves united on Federal issues. I'm looking forward to some real achievements in these areas.



Melinda, Angus and Declan

Melinda Ewin (QLD)

I am a parent of 2 delightful boys, Angus (9) who has autism, and Declan (8). Angus is a happy boy, who enjoys the company of his peers. His disability, however, produces differing coping strategies to stress and sensory input that are not considered 'normal' reactions for children. In some situations these behaviours can be interpreted as being naughty, and not as a response that has been filtered through an autistic mind. At the moment, our main battle is with education issues, which is a common problem for parents of school aged children.

I work as a Systems Advocate Worker with Queensland Advocacy Inc. I advocate for people with disabilities on a systemic level and as my 'hobby', I also advocate for systemic change in the education system. My goal is only to have teachers that appreciate the uniqueness of our children, and pass that appreciation of uniqueness onto our children's peers and the next generation.



Jan De Witte

Jan De Witte (VIC)

I live in Hoppers Crossing in Melbourne's Western Metropolitan region with my son, Donald, and husband, Clem. Donald has Aspergers Syndrome (an Autism Spectrum Disorder). Apart from being on the Committee of the Australian Association for Families of Children with a Disability, I'm also Chairperson of Parent to Parent West and convenor of the Western Region Autism Spectrum Support Group. I'm also involved in various parent advocacy networks trying to achieve a better deal for children with Autism and Autism Spectrum Disorder.

On the national scene, key issues for me include better co-ordination between the Federal Government (including Medicare) and State/Territory governments to ensure that Autism assessments can be done quickly and thoroughly without huge costs to parents. Early Intervention and education, particularly in the teenage years are also huge issues for our children.

Australian Association for Families of Children with Disability

Committee Members

ACT

Cheryl Patrick
Karen Connaughton

Northern Territory

Bruce Young-Smith

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
Clara Harris

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