



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

Parent Voices

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It has certainly been a busy and interesting time for parents of children with disability and others who have a connection to the disability field. The Carer Allowance debate really put disability on the front page and made the general public aware of some of the difficulties which we face every day.

I've received many telephone calls from parents about their own situation regarding the Carer Allowance. I am amazed that so many parents don't know their rights, not just about Centrelink, but also in other areas — be it education, local council services, respite etc.

As parents, we have to know 'the rules of the game', for each and every one of the services our children are entitled to. When a service or funding body is not delivering what it should be, we need to be strong and active in voicing our concerns until a satisfactory resolution is achieved.

This principle applies to both individual families and at the broader 'systems' level, to politicians and government departments.

I am currently a representative on three important national committees, all of which provide an avenue to have a positive influence on Federal Government policies:

(i) Centrelink Customer Reference Group — where senior staff from Centrelink and the Department of Family and Community Services (FACS) are forced to listen to complaints and suggestions about disability and parent/carer related issues, including Carer Allowance and Carer Payment.

(ii) Carer Allowance Review of Lists of Recognised Disabilities (see sidebar).

(iii) National Family Carers Voice — a new group combining people and organisations across the full range of 'caring situations', set up by Minister Vanstone to provide her with policy advice.

I'm also just about to finish a four year term on another important committee, the National Disability Advisory Council (NDAC).

Of course, in-house government committees aren't the only way to have a positive influence on government policy, but we need to make the most of the opportunities that are there.

Please contact me with any issues you'd like to see on the agenda of any of the above committees. Via National NoticeBoard I'll endeavour to keep you up to date with the issues discussed and any positive outcomes.

Meanwhile, as evidenced by the Carer Allowance debate (and prior to that, the success with Childcare and the Special Needs Subsidy Scheme, see National NoticeBoard editions 6 and 7) when parents energise and take the opportunity to tell the powers that be, loudly and clearly, what life is really like, sometimes they do actually listen and sometimes they do respond in a positive way.

Barbara Alexander AO
Convenor AAFCD



Senator Amanda Vanstone,
Minister for Family and
Community Services

On 12 August, 2003, the Minister for Family and Community Services, Senator Amanda Vanstone announced:

1. Six disabilities are to be added to or modified on the Lists of Recognised Disabilities that give automatic access to the Carers Allowance. The disabilities are: Down syndrome, Cystic Fibrosis, Epilepsy (uncontrolled), Haemophilia (moderate), Phenylketonuria, and Fragile X syndrome.
2. Anyone with one of these conditions will now be eligible for the Carer Allowance without the need for further medical assessment prior to their 16th birthday.
3. A review of the Lists of Recognised Disabilities is also in train and will be undertaken by an independent panel of medical experts and carer representatives.

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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



Josh's Story

Seven years ago, I wouldn't have imagined contemplating the process of integration. Yet this simple word has been part of our lives for the last three years; and it hasn't been a simple task. Our son Joshua is 7 years old and was diagnosed with severe autism at 3½ years of age. Josh's life is even more complicated as he has severe life-threatening food allergies, food intolerances and chemical sensitivities.

Josh is anaphylactic to peanuts, nuts and eggs (this means that he could die if he comes into contact with any of these foods). He is also allergic to dairy, soy, fish, wheat, pollen, dust mites, dogs, wattle, feathers, perfume, cleaning chemicals, formaldehyde, chalk, sulphites and so on. He can only eat potato, swede, lamb, sugar, water, rice bread, rice and maple syrup.

Josh's environment plays an important role in the state of his health and development. He can't go on school excursions because the smell of diesel fumes on the bus makes him sick. New carpet at school or painting the walls will cause allergic reactions which inevitably lead to a secondary infection such as an ear or chest infection.

Last year a new eucalyptus fence was built at his school. The smell of the fence caused Josh to get a chest infection and he had two weeks off school. This is quite commonplace. Preservatives in food or simply the wrong food will lower his immune system's resistance to infections. Josh has had several lots of grommets, his tonsils removed, adenoids removed twice, a minor collapsed lung and so on. Every time Josh has a reaction or gets sick his autism behaviours worsen greatly.

For two years Josh went to a small kindergarten where he attended part-time. He was often away sick due to his allergies. This year he transferred to a smaller school. We chose this school, even though we are out of the area, because it doesn't have a school canteen and this minimises his contact with potential allergens. They also had some experience with children with autism and were willing to take on the task of Joshua's allergies.

We began discussions with the school to prepare them for Joshua's arrival and the school embraced Joshua right from the start. Challenges have been met and overcome with the support of the principal, the staff and the local community. It hasn't been easy. It



Josh

took lots of meetings with myself and the staff and support workers to develop an understanding of the complexity of Joshua's problems.

At the beginning of the year, the Principal and Josh's Teacher organised meetings with parents, which were very well attended, to explain Joshua's allergies. The parents were apprehensive at first but after explaining Joshua's problems they were totally supportive of Josh being included. The staff also had a session with St John Ambulance on how to use an epipen (to administer adrenaline). Every staff member attended this session. All the staff working with Josh stopped wearing perfume and stopped eating nuts and eggs at school.

It would be easy to say no to our requests due to a lack of money or some other reason, but this didn't happen. Filters were purchased for his room to clean the air. Equipment was also purchased to help distract him when he has a reaction. These things have meant that Josh can attend school for approximately half a day, four days a week on average.

Because Joshua's illnesses affected his attendance at school, we approached the Education Department with regard to providing some aide time for Josh in our home. Josh was eligible for approximately 27 hours and we were hoping that this could be shared between the school and home to maximise Joshua's education program.

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I also approached the Association for Children with a Disability (Tas) and with the help of an advocate we worked through exactly what Joshua's needs are and how they can be addressed. The advocate has since met with the Department of Education and discussed various options for Joshua's education.

We are still working on how best to address his needs and this will probably take many more meetings. As these times can get very emotional, having extra support has been my lifesaver. We hope we will be able to

cater for Joshua's needs both within the school and home. This is perhaps the only way Josh has a chance to learn.

Joshua will always face huge problems in his day to day life. He will always have reactions and sometimes we don't always know what causes it. To be included in a 'normal' school environment so openly has given Josh a chance of having a life outside his home. This is something which we didn't think would ever happen.

Annette Wyley

Working Together

Our Association is working closely with the Equity and Standards Branch of the Tasmanian Department of Education with the implementation of their Inclusion Policy which was introduced in 2000.

Prior to 2002, the Equity and Standards Branch acknowledged that our Association's Advocacy Service was being called on to assist families when difficulties arose within the school system. They managed to find some funding to enable our Association to increase the hours of advocacy we could provide to families. This funding arrangement was incorporated in a formal Memorandum of Agreement between our two organisations.

The Memorandum of Agreement recognises that the Department of Education supports the concept of advocacy services for families of children with a disability and believes that a family advocacy service can play a key role in providing input to consultative processes concerning services for students with disabilities in government schools.

Our Association and the Equity and Standards Branch meet regularly and discuss issues and areas of concern. In cases where it is difficult to find appropriate solutions these cases are discussed and we are referred to someone who may assist in resolving the problem.

It has been nearly two years and I can say that in the beginning I was sceptical about whether or not the proposed partnership with the Department would work. Down the track, I am very pleased that we have been able to highlight particular 'hot spots' around the state with the Department of Education, which then in turn gives them the

'ammunition' to be able to address issues and hopefully find solutions in a positive and pro-active manner.

It is a credit to the Minister for Education in Tasmania, the Hon. P Wriedt MHA, that the Disability Standards for Education have been signed off with the Commonwealth Government.

Tasmania has always been recognised as one of the leading states in the area of inclusion of children with disability into mainstream schools. As long as the Department of Education continues to be pro-active in their search for excellence for all Tasmanian students, we hope we will soon overcome the barriers to truly inclusive education.

Helen Radcliffe

Association for Children with a Disability (Tas)

Education Advocacy

State/Territory governments vary markedly in their approach to education for students with disability and their commitment to support for families and schools. Let us know about your experiences of schools and education — positive and negative — and your suggestions for improvements. Federal and State/Territory governments should be undertaking. Contact Barbara in our national office 1800 222 660 or barbaraa1@inet.net.au.

The Federal Minister for Education, Science and Training, Dr Brendan Nelson, is introducing new Disability Standards for Education as part of the Disability Discrimination Act. Contact Barbara for further details about the implications for your State/Territory or see <http://www.ozemail.com.au/ddasp>.

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
Barbara Alexander AO,
8 Grubissa Court, Benalla, Vic,
3672 or e-mail to
barbaraa1@inet.net.au.

Clara Harris (WA)

My name is Clara Harris. My husband, Damian, and I have a beautiful little man, Sam who is 5. Sam is a charming little rat bag who can melt your heart in a second with his cheeky grin and mischievous blue eyes. He's a bit of a whiz on the computer, loves Sesame Street and the Wiggles, is extremely loving and affectionate and was diagnosed with autism at two and a half. He is virtually non-verbal but has no signs of an intellectual disability.

We live on our farm at Binnu in the midwest of Western Australia, one hour north of Geraldton (about five and a half hours north of Perth). We crop nearly all of the farm with wheat and lupins and have about 50 head of cattle.

Our road to diagnosis and finding services was not easy to say the least. Living in a rural area certainly provided extra challenges! Sam now attends kindergarten with full aide time and is participating in everything and having a great time!

We must be the luckiest people around as our family, friends and the entire community have been very supportive. We could not have had the results we've had without this support. Being a parent can be hard work at the best of times. Add disability to the equation and things can begin to overwhelm you. I would like to think that anybody who needs help would receive help, regardless of where they live, what they do or who they are. Somehow, it must be that easy. A person with disability is, first and foremost, a person.

Clara Harris



Sam

"He's a bit of a whiz on the computer, loves Sesame Street and the Wiggles, is extremely loving and affectionate and was diagnosed with Autism at two and a half."

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
Julie Brunsten
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.

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