



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

Standards for Education

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From your input to our 'Top 3' Priority Issues questionnaire, I was really surprised to see that education features as a key issue in every state. Our children spend more than a decade at school. It is so important to get all the elements of the school/education system right from day one.

The first issue is for every family to have a genuine choice of school for their child. Some parents make a clear choice from an early stage that a special school is the best option for their child. Others believe that their child has a right to quality education in a mainstream setting and are prepared to battle every inch of the way to make sure it happens. Some prefer the option of dual enrolment, part of the week in a special school and part in a mainstream school.

For some parents, the government school system is their preferred option. Others want their children to be able to attend a religious based school or another independent non-government/private school.

Our Association has a 'pro-choice' approach to education. We believe every parent/family should have a genuine choice of school for their child with a disability. Unfortunately, we are a long way short of having genuine educational choices for our children.

Two issues stand out for immediate attention by Federal and State/Territory governments: (1) Improving the skills and attitudes of teachers and Principals in mainstream schools towards the inclusion of children with a disability and (2) Funding anomalies in

some States/Territories whereby individual disability education funding (supposedly 'attached' to the child) is not portable between different educational settings. For example, in Victoria, a child with a disability in the independent/private school system attracts a much lower level of individual disability support than if they were to attend a government school. This leads to the absurd situation where families feel forced to send their child to a different (government) school than their siblings who may attend a Catholic or independent school.

At the time of going to print, Federal and State/Territory Education Ministers were meeting in Perth to discuss a new report on Disability Standards for Education as part of their Ministerial Council on Employment Education Training and Youth Affairs (MCEETYA). Once adopted, the new disability education standards will be put into legislation (hopefully in time for the 2004 school year). This will help to clarify the exact meaning of various sections of the existing Disability Discrimination Act regarding schools and education.

We'll keep you informed of developments which might assist you to get the best out of the education system for your child. I've appreciated hearing about your experiences of education and your suggestions for improvements. You might even like to consider writing an education story for National NoticeBoard.

Barbara Alexander AO
Convenor, AAFCD



Barbara Alexander, AO
Convenor, AAFCD

Make sure you are on our mailing list to receive future editions of National NoticeBoard directly. See the Registration Form on page 4 or simply ring through your details on our free call number 1800 222 660.

Also, encourage others you know - parents and service providers - to join the mailing list and enjoy the benefits of National NoticeBoard. National NoticeBoard is a free publication.

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The Australian Association for Families of Children with Disability (AAFCO) is auspiced by the Association for Children with a Disability. For updates and more information see www.acd.org.au

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www.telstrafoundation.com

The Reecey Ram Story

This story is about our family and our two beautiful sons, Callum and Reece. Reece has a developmental delay and Callum is a loving big brother. Even though Callum is fine and well, we need to tell you a little bizarre history about his welcome to the world and the twist to the tale is our Reece.



Kylie and Reece

"I can't believe parents are not given some credit for their daily observations and the connection a mother has with her child. Parents can sense if their child is not OK and they should be listened to and acknowledged."

"When the review was over, the social worker got up and just walked out. Craig and I were crying in the hallway, devastated by what they had just told us about our beautiful little blonde haired boy. Where was our support?"

My husband and I were excited to learn that I was pregnant with our first son, Callum. My pregnancy went really well, besides growing to the size of house, but the birth was a horror story! My labour was over 21 hours and I had excruciating back pain. It came time to push and there was a problem - Callum was stuck. We were experiencing what is called shoulders distotia. There was quite a panic and it took them a long time to get him out. By the time he was born the stress had caused his body to shut down. He was not breathing and his little body was not responding. It took about 20 minutes to revive him and I was sure that he was going to be brain damaged. He was on oxygen for 4 days and in special care for ten days.

The diagnosis wasn't too good. They thought he might have delays in his development, and that he could have sight and hearing problems. But by some miracle, our little angel has had no developmental problems whatsoever. We were so happy we decided to have another baby.

I fell pregnant straight away and everything went well except that I got gestational diabetes. Due to the problems that with Callum's birth, I was advised that I was unable to have a natural labour.

I picked the date of my new baby's birthday (seeing as how I could). The day arrived and my baby was born. It was such a beautiful birth as our baby came out crying, not like Callum (no sound). He was a healthy little boy and we were so happy. We named him Reece.

Not long after he was born, our paediatrician did a full check on him and discovered that he had a significant heart murmur. On Day 2 we took him to see a paediatric cardiologist in Sydney and the doctor felt that it would repair itself without concern. We had regular 6-weekly check ups with our paediatrician who said his development was fine.

When he was about 4 months old we had to call an ambulance because he was having trouble breathing and was very congested;

he had croup. Even though this is a common ailment, this was when we felt our little Reece was not the same. He left the hospital and they said that if he had trouble breathing we should squirt some saline up each nostril. I sat by his bed and did this night after night. I kept taking him to my local GP who insisted it was a natural product to use and harmless. At the time, I thought, I shouldn't have to do this to my son nearly every night; this was not normal. As time went on, he did not get any better and my GP said I was just a paranoid mother.

'Paranoid mother' — a term which is used far too often. I can't believe parents are not given some credit for their daily observations and the connection a mother has with her child. Parents can sense if their child is not OK and they should be listened to and acknowledged.

After this, I was angry and I wanted help. Reece was now 5 months old and close to being hospitalised for a severe chest infection. He was having trouble breathing and was coughing so much that he popped blood vessels in his eyes. He was on a nebuliser, antibiotics, not sleeping well and starting to show signs of development delay.

The cough, chest problem and congestion continued. Reece was now 9 months old and he was not sitting properly or rolling and he would grab his head in pain. The wind blew the door shut with a loud bang one day and he didn't even twinge. We banged saucepans behind his head and he didn't turn to look.

We were sent for a hearing check and Reece didn't respond to a single test they did. They were obviously concerned and implied that there was something wrong but were not clear. In the next breath they said come back in 3 months and have him tested again. I couldn't believe it! I walked out of there saying to myself out loud, wait 3 months? NO WAY!

It was now obvious that Reece had a delay in his development; he was in a world of his

own. I went to another GP who diagnosed him with an ear, nose and throat infection.

We were then referred to an ear, nose and throat specialist who took one look in Reece's ears and said that they were full of fluid and that he needed grommets. He had also been referred for a developmental assessment, to take place exactly a week after he had the grommets inserted.

The assessment seemed very positive. We watched our son attempt to do things and he was 100% more active and involved compared to the previous week (before the grommets). We had to wait in the hallway for 40 minutes while the doctor wrote up her findings. We were finally called in and I could tell by her body language that the news was not going to be good. The social worker just sat there looking on like someone had died.

We were told that Reece had a serious global developmental delay and that there could be no accurate prediction of his future development. At 13 months he was presenting as a 7 month old. We felt she repeated a lot of what we had told her and we both found the way it was conducted extremely negative and grim.

When the review was over, the social worker got up and just walked out. Craig and I were crying in the hallway, devastated by what they had just told us about our beautiful little blonde haired boy. Where was our support?

The social worker phoned me about 2 weeks later and said, "Oh by the way, I forgot to tell you that you are entitled to a Disability Allowance". I was at no stage to accept or even acknowledge my son had a disability, so I was quite abrupt when speaking to her.

Around this time, I met the community worker from the Early Intervention team, she was a breath of fresh air. Someone who listened and started to help us to help him. Reece started seeing a physio and doing home-based learning every fortnight. They were helpful, encouraging and supportive. The staff were easy to talk to and understanding of my situation. We were also referred to family groups. These were in a preschool/playgroup setting with two dedicated specialist workers who worked on fine motor skills, stimulation, socialisation and speech. This was my support network 2

hours every week and my quality time helping Reece. We were placed on the waiting list for speech therapy and O.T., which we never received. I think we are still on the waiting list for speech (4 years later).

I was advised Reece should start child care/preschool when he was 2 years old and we were extremely lucky to receive some SNSS funding. The staff at the preschool absolutely adored Reece. The person they employed with the funding worked with him brilliantly and was constantly pushing his barriers but in a very supportive way. Every day when I picked him up one of the staff would tell me excitedly about little things he had done. They understood that the little things they do are huge. We received SNSS for the whole time he attended child care/preschool and I believe this has been crucial to his quality of life.

The next step was to make a decision regarding school. I researched every option and visited every class in the public school system before I made my decision. We started him at a special school and he found it a breeze. He loves his teacher and catching the bus. I can't put into words the fantastic work these teachers, aides and volunteers do at this school.

Reece is now 5 and a half years old, his speech is slow but we are talking more and more as the weeks go by. He loves fish and pet shops; I have been to every Aquarium in our region and on a regular basis. The shop owners all know him.

We don't know what the future will hold for our darling Reece, but we will make sure that he gets to be involved in whatever interests him. Reece has changed our life for the better. We are better people, we have made some special friends and appreciate the little things in life. Reece has given me a career which I would never have had. I have studied Welfare for the past 3 years and achieved highly (which I never really did at school). I have also been given the opportunity to be part of the Australian Association for Families of Children with Disability and I will endeavour to do all that I can to help families get what they need and deserve.

Kylie Ramstadius
Mangerton, NSW

"When Reece was 13 months old, I met the community worker from the Early Intervention team, she was a breath of fresh air. Someone who listened and started to help us to help him."

Your Story?

Has Kylie's story inspired you to consider writing your own story for National NoticeBoard?

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.



Centrelink 'Saved' Cases Review

In 1998 a new assessment method was introduced for Carer Allowance (previously known as Child Disability Allowance). Centrelink 'customers' who were receiving a Child Disability Allowance at that time were medically reviewed prior to the introduction of this new assessment. Those found to be medically eligible under the old Child Disability Allowance rules were advised that they would continue to receive payment without a medical review for five years.

On 30 June 2003, this five-year period ended. Legislation requires Centrelink to assess whether these 'saved cases' can continue to receive Carer Allowance under the new assessment method. According to Centrelink, the new method targets assistance to carers of children who have a more severe disability or medical condition that affects their ability to function at a level appropriate to their age.

Review forms and letters from Centrelink started going out in late June 2003. The form consists of two sections. One section needs to be completed by the 'customer'/family and the other by the child's treating doctor. If you are one of these 'saved cases' and you cannot return the Review form to Centrelink

within 28 days of receiving it, you can contact Centrelink on 13 2717 and request an extension to lodge (and they can also help with completing the forms or answer any queries about the review). You can also contact the Association office for advice on 1800 222 660.

Other Centrelink/financial issues

Thanks to everybody who contacted us about Carer Payment and other Centrelink/financial issues after the articles in the May, 2003 National NoticeBoard.

If you feel inspired to write your story and/or suggestions regarding Centrelink/financial issues for inclusion in National NoticeBoard, please do. These 'real-life' stories are a key element of our advocacy work to inspire politicians into action.

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.'

AAFCD 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
Melinda Ewin
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:

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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