



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 2

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Strength in Numbers

Our first newsletter was a great success. We managed to cover a great deal of Australia and we received many enthusiastic replies and phone calls from parents and service providers. We have also been successful in finding additional parents to be our points of contact.

Your response to our Top Three Priority Issues has led to emails, letters and faxes detailing how you are feeling about the lack of support for families. Many of you feel your load could be significantly lightened if only you were able to access the services you need when you need them.

If you haven't yet sent back a registration form, you will notice that there is a 'Mailing List Registration and 'Top 3' Priorities Input' form inserted in this edition asking you to tell us about your issues, the ones that you feel would make your life better if they were appropriately addressed.

While we have had a great response to the first newsletter, we need many more replies. If you are sitting there thinking, 'Oh they don't want to hear from me', we do! The more replies we receive, the more chance we have of lobbying on your behalf and putting together a policy document that represents all families, all disabilities, no matter where you live in Australia - there is strength in numbers!

Some of the issues that parents have mentioned so far are: respite services;



Barbara Alexander

appropriate recreation programs for teenagers; a scheme to cover vehicle modifications for families whose children need wheelchairs and other types of equipment; as well as additional funding for equipment. These are just the tip of the iceberg.

Some parents have written heart warming statements about how they struggle financially to cope, how they have had to forego their careers, how no-one seems to understand their predicament and how they sometimes feel no-one really cares. Well, we do! So please send in your registration forms and your issues and we will use this information to make others care.

Barbara Alexander AO

This newsletter should include a 'Mailing List Registration and 'Top 3' Priorities Input' form as a separate insert. If you require more copies, phone 1800 222 660.

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Quicknote:

Negotiations are continuing between Federal and State governments on a new Commonwealth/State Disability Agreement (the CSDA).

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

A life changing experience

Like most expectant mums, I worried about the growing baby inside me, but my doctor assured me that everything was progressing well. One week before my due date, I was hospitalised with pre-eclampsia (excess fluid and high blood pressure), but was released four days later.

On my due date, labour began at 1am and my husband, Chris, rushed me to the Gold Coast Hospital. After close monitoring, my waters broke. Then panic set in as the midwife realised the umbilical cord was prolapsed and oxygen was being cut off to our unborn child. I was rushed to theatre for an emergency caesarean, but our daughter Katelyn was born without a heartbeat. She was revived and transferred to the Mater Mothers Hospital in Brisbane. She remained in a critical condition in the Intensive Care Unit for one week and was then transferred back to the Gold Coast Hospital for another two weeks. We kept a vigil at Katelyn's side the entire time, hoping that she would be all right.

Finally, the doctor gave us the good news and told us that Katelyn was able to go home, we were so excited. The doctors told us that she would be fine, we were so relieved. By the time Katelyn was almost twelve months old, we began to realise that she was not reaching all the normal milestones. Our pediatrician gave us the life altering diagnosis that Katelyn had Cerebral Palsy.

We were devastated and unsure what the future would bring. We researched all the relevant information but were still in denial for quite some time. Katelyn began having treatment to improve her physical condition including physiotherapy, occupational therapy, and speech therapy and has access to various pieces of equipment such as a standing frame, special chair and cut out table. She is a very positive and determined little girl; we are very fortunate. She works extremely hard to succeed in everything she does.

My husband and I try to remain positive and focused for Katelyn although, at times, it can be very challenging. Our philosophy is to take it one day at a time. At the age of two, Katelyn started having seizures and was diagnosed with



Katelyn

epilepsy, apparently also very common in children with Cerebral Palsy. We were living on eggshells as she was having seizures every day. After a while, we started to become nervous wrecks and were constantly on guard and waiting for the next one. Nevertheless, we have survived and she is now on more medication to control the seizures and we live in hope that she will overcome them altogether.

Our lives are very hectic with all the daily therapies she has, but we believe they are so beneficial for her that it is worth all the hard work. Most people ask us how we cope with our lives today. How can we not cope? We have to remain positive for Katelyn as she has so much potential and understands so much and she is our little girl, regardless.

My parents brought me up in a very loving and positive environment, which has helped me immensely to deal with Katelyn's condition. I also have the support of my husband, who is my rock and loves Katelyn unconditionally. Our friends and family have also been a tremendous support for us.

Having Katelyn has made me realise that life may not bring you all that you had hoped for and it may not be perfect, but this whole experience has made me a

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much stronger person with a totally different outlook on life.

Katelyn has just turned three and is unable to walk, but she can crawl and pull herself up on furniture, which is wonderful. Recently, Katelyn was given a new lease on life. With thanks to the Lions Club of Burleigh, she received a Hart Walker, which enables her to walk independently. She is so happy and we are extremely pleased for her as it enables her to move around on her own.



Katelyn and Claire

After careful consideration, my husband and I decided to have another child and Katelyn now has a little sister, Claire, whom she absolutely adores. I am glad that we decided to have another baby, even though it is very demanding, it has helped me cope with everything and Claire is such a placid baby.

Katelyn is such a special little girl and her efforts to succeed in life with Cerebral Palsy make us all very proud.

Karen Rogers
Merrimac, Queensland

"After careful consideration, my husband and I decided to have another and Katelyn now has a little sister, Claire, whom she absolutely adores."

Child Care, Vacation Care and the Special Needs Subsidy Scheme

Access to good quality affordable child care and vacation care is a 'life-saver' for many families of children with a disability. The SNSS program has, overall, been a great success in promoting the inclusion of children with a disability within various child care settings.

We were very disappointed that the federal Budget didn't include an increase in funding for SNSS. We are also extremely concerned at reports of increased waiting lists for SNSS and reduced access to child care because the SNSS funding isn't stretching as far because of increased costs. If you are or have been affected by inadequate SNSS funding, please contact us on 1800 222 660 with the details.

Also, if you have a positive story to tell about the value of SNSS and child care, please consider writing your story for National NoticeBoard. Positive stories will help us 'sell' the value of SNSS to Federal decision-makers.



Back Copies of the Victorian-based Association for Children with a Disability magazine, 'NoticeBoard' are available (free) from the Association, phone 1800 654 013 or mail@acd.org.au

CSDA Research Papers

Various research papers relevant to current negotiations on the Commonwealth State Disability Agreement include:

1. Nucleus Group Report:

'Review Current Responses to Meeting Service Needs of People with a Disability and the Effectiveness of Strategies to Support Families'

See: <http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/research?Open#review>

2. SPRC (Social Policy Research Centre) Report:

'Methods to address requirements for changes in funding Disability Services brought about by external change'

See: <http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/pages/research?Open#methods>

3. AIHW Report (Australian Institute of Health and Welfare)

'Unmet Need of Disability Services: Effectiveness of Funding and Remaining Shortfalls'

See: <http://www.aihw.gov.au/publications/dis/unds-efrs/>

For more information about these reports phone Chris Allen in (03) 9616 8367.

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



Steven, Cheryl and Ben Patrick

Cheryl Patrick (ACT)

My name is Cheryl Patrick. My husband Steven and I have 3 sons, Ben (14), Matthew (13) and Luke (10). When Ben was 6 months old, we were told that he had Cerebral Palsy, something I knew next to nothing about. It was to take me on a totally new learning curve in my life. On Ben's 10th birthday, he became the proud owner of an electric wheelchair, which has made a huge difference to his life and independence. Ben is now in year 9 at our local High School.

I have been involved with various groups and organisations over the years: Friends of the Brain Injured, Child Health and Development Service, Client Consultative Group, Advocacy Action ACT and the Cerebral Palsy Support Group. I have also been involved with several reviews over the years: Special Education, Therapy Services in Schools, Needs Assessment Tool and most of these issues are ongoing. The vision of my son's future and the future of all, I am sure, will keep me involved in similar activities in the years to come.



Leonie McKnight

Leonie McKnight (QLD)

I'm Leonie McKnight, mum to Craig (eleven this year) who has a rare mitochondrial metabolic disorder of which very little is known and for which there is little or no successful treatment. This has left him completely reliant on others for all his physical needs and although he has no obvious intellectual disability he has no speech, so life is quite a challenge.

We live in Roma a small town in south west Queensland, six hours by road from the Specialist Medical care that Craig require. We are very aware of issues faced by families with children with disability in rural and remote areas.

I have long felt that it is important and necessary to articulate the issues that we face daily to the systems (eg Health, Education and Transport) that find our children so challenging.

I am a member of a number of groups that work locally and statewide to highlight these issues and I am delighted that there is now an opportunity to tackle these issues on a national level. My specific focus is family based, as I believe there is little comprehension at a System or Government level of what families in our situation go through and need.

I am pleased to be able to support and work with the other members of the Association and look forward to the positive outcomes that such a far-reaching and progressive organisation will achieve.



Rob, Michael, Clare and Shane Masolin

Clare Masolin (WA)

Hi, I'm Clare Masolin. My husband, Rob, and I have two boys, Michael (6) and Shane (22 months). Michael has Cerebral Palsy following complications associated with his premature birth in Darwin. We moved to Perth when Michael was two and a half in order to access specialist medical and Cerebral Palsy facilities. Whilst in Darwin, I was involved in the infancy of the 'Territory Special Needs Support Network' and am now active in 'Parent Focus', an informal group of parents of children with Cerebral Palsy who meet monthly to share ideas and information in a highly supportive network.

I have a background in finance and lending, am a qualified Primary and Austswim teacher and have a passion for stained glass!

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 Binnu

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