

# National NoticeBoard

Newsletter of Australian Association for Families of Children with Disability (AAFCD)

## Blurring it Out

Sometimes I get really angry and emotional about my situation and that of other families I know.

One night before the last Federal Election (before I was the AAFCD Co-ordinator), I sat down and wrote a long email to the Minister for Family and Community Services, Senator Patterson, which I also sent to other politicians as well as friends and family.

I just sat down and blurted it all out. I didn't hold back. While I was angry when I was writing, it felt good to be letting go of my emotions and telling the world how I felt. By the time I finished and pressed the 'send' button, it was very late at night (getting towards breakfast actually!).

The response to my email was amazing. It seemed to bounce around cyberspace with various people and networks forwarding it on to others. I even received a few copies of it myself from being on different email lists!

An edited version, 'To Senator Patterson and all other State and Federal Ministers and Shadow Ministers' was published in the July 2004 edition of National NoticeBoard (Edition 14). My original was full of CAPITALS, underlines and lots of multiple exclamation marks!!!!!! But they were all part of the reality of how I felt when I wrote it. I would have used lots of double underlines if the computer would have let me!

Of the many responses I received from parents, in this edition we've published one from Roy Shaw of Whyalla Norrie in South Australia (see page 4). When Roy first contacted me, we got talking and soon found we had lots in common.

I found the positive way that Roy talked about his son really inspiring. When I suggested he write his story for National NoticeBoard, he told me he wasn't much of a writer, but that if it would help other children and parents, he'd give it a go.

Roy's story is a perfect illustration of what families of children with a disability need from the Federal Government in this year's Federal Budget.

I challenge the Prime Minister, the Treasurer and all other federal MPs to read Roy's story and then look me, Roy (and the rest of us) in the eye and say that we don't deserve an increase in the Carer Allowance, and for those children requiring nappies on a permanent basis, some extra help with the cost of nappies.

We don't expect governments to solve all our issues, but providing a basic level of services and income support for children, young people and adults with disability is a role for government.

I am sick to death of families of children and young adults with disability being overlooked in the political decision making process of governments.

There had better be something decent in this year's Federal Budget for families like Roy's, or else the Treasurer might find me camped on his doorstep, angry and emotional once more. I don't know whether Roy would be able to join me there, or whether you would too. Let's hope the Treasurer gives us reason not to feel so angry.

Helen Johnson  
AAFCD Co-ordinator

### National NoticeBoard Direct!

To get National NoticeBoard mailed directly to you at home or work, you need to be on our subscription mailing list. It's FREE for families. Contact me on 1800 222 660 or by email ([helenj@aafcd.org.au](mailto:helenj@aafcd.org.au)) and I'll send you our new pamphlet with all the details.

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Federal Treasurer, Peter Costello

May 2005 will see Peter Costello deliver his ninth budget. Last year's budget included a one-off \$600 'bonus' payment for the Carer Allowance.

Will this year's budget see this 'bonus' incorporated as a regular yearly payment for families of children and young adults with disability? What else might the budget promise for our families?

### Inside this Edition...

Tantrums and Triumphs, page 2

Federal Budget Priorities, page 3

Stretching that Rubber Band, page 4



Australian Association for  
Families of Children with Disability

# Tantrums and Triumphs

I'm Jill, Joseph's Nanna. As Joseph's family has always lived with me, I have been there to see all the highs and the lows of our little man. Until Joseph arrived, we knew very little about autism, but we soon learnt—about compulsions, tantrums, tears and rewards.

Joseph was born quickly, with the result that his head was very purple. He was also born with a small round birthmark on his foot, a tiny red one between his thumb and pointer finger, and a hernia in his tummy. He was not diagnosed as autistic until he was two years old. Had we known more about it earlier, we may have picked up the signs that were already emerging.

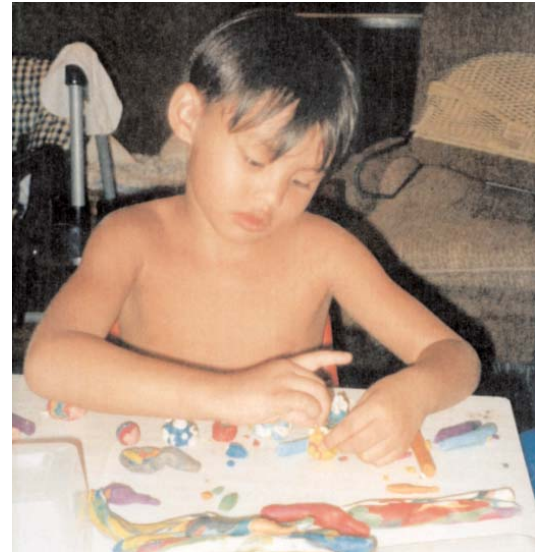
As a baby, Joseph would become very unsettled when visiting other people, and he would always cry to go home. By the time he was two, he was clock-like. After enjoying himself for one hour, almost on the dot, he would grab hold of us and point to the car. To stay any longer totally distressed him.

Joseph would rarely make eye contact, until his uncle eventually solved this for us. He brought home a long pipe from an air conditioner that we would look through and say, "Boo!" This greatly improved Joseph's eye contact with people, although he still squeezed his eyes shut at things or people he didn't want to see.

We have had to deal with Joseph's many compulsions and the tantrums that follow if things are moved from their set order. If one of his rubber blocks was moved, he had to set them back up in order. Sometimes he would try to carry all five blocks together and got very upset if he dropped one. But the egg compulsion was the worst one. We had to hide the eggs and keep the fridge locked. Walking past the eggs in the supermarket was a real nightmare.

As important as his compulsions are, so changes are stressful to him. Walking a different way to preschool or the shop is very traumatic for him, and it was a long time before we achieved this without a tremendous battle.

A mirror turned out to be an enormous help in combating his worry about things being different. Joseph did most things in front of the mirror, so if something was not the same as usual, he was able to look at it in the mirror instead of looking directly at it.



Joseph with his play-doh

It's very hard to cook meals while Joseph is around. The steam from the frying pan fascinates him, although he can now sense pain and pulls back quickly.

Tantrums have been rife at times, often over what may seem trivial to us. We have had jelly thrown all over the floor and stomped in because he couldn't eat it in the lounge room. I have physically carried him, screaming, from the shops because I wouldn't buy him eggs, and he has screamed all the way to his sister's school because we didn't go to the shop first.

Things have been so very difficult at times. Some nights he will scream for hours on end and we are unable to pacify him. Videos that he loves one day, frighten him the next. Keeping clothes on him is especially hard. It took ages before we were able to get, let alone keep, his school T-shirt on him, thanks to the help of a very caring preschool teacher. He is clever and always knows which school he is going to (special or mainstream) by the colour of the T-shirt he has to wear.

Joseph is a great escape artist and we have had to search for him a number of times, even though our gate is always firmly shut. He is a great climber and can scale anything. He got up on the roof in the pouring rain one day and refused to come down.

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"As important as his compulsions are, so changes are stressful to him. Walking a different way to preschool or the shop is very traumatic for him, and it was a long time before we achieved this without a tremendous battle."

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"His milkshakes are also a wonder to behold. They may consist of milk, apples, mango (complete with the skin), lollies, fruit juice, pickled onions and anything else he can get his hands on. Delicious!"

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## Your story?

The parent/family stories are the most popular part of National NoticeBoard and we always need new stories.

If you feel inspired to write, please do!

Send your story and a photo (all photos are returned) to:  
Helen Johnson  
AAFCO Co-ordinator  
590 Orrong Road  
Armadale, Vic, 3143 or email  
(helenj@aafo.org.au).

He loves making pizza. He throws the dough up in the air and catches it like they do on TV, which makes for a very messy kitchen! His milkshakes are also a wonder to behold. They may consist of milk, apples, mango (complete with the skin), lollies, fruit juice, pickled onions and anything else he can get his hands on. Delicious!

His teacher from the special school solved the problem of haircuts for our little man by being very patient and caring. She gradually introduced Joseph to sitting quietly while having his hair cut. Previously, it had taken all of us to hold him down while he screamed in terror.

Joseph draws beautiful pictures and copies writing exactly as he has seen it. His memory for detail is amazing, but his real talent has emerged through his play-doh. He makes the people, creatures and things he sees on his videos. When he is finished, they look exactly like the ones he has copied, down to the finest detail. They have to be perfect for him to be satisfied and they are truly beautiful.

When Joseph joined a group at Carpenteria Disability Service, he learnt so many things,

as did we. We found out about such things as picture exchange, Makaton signing and, especially, that there was support for us.

His preschool and school, along with his many therapy sessions, have helped so much and Joseph has come such a long way. He is talking a lot now and interacts with other children and adults, and he can use his communication and exchange board.

Our little boy has made great leaps ahead in the first seven years of his life. When I think back, it seems that some days we have taken one step forward and three steps back. Yet, as I look at Joseph matching pictures or playing with his sisters, I know that every moment of the struggle has been worth it, for both him and us. He has come so far and brought us so much love along the way.

Life with our beautiful, autistic boy who is trying so hard to cope in what to him is a strange world, will always be full of ups and downs, challenges and frustration. But it will always overflow with excitement, rewards and love.

Jill McGee, Anula, NT



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"His memory for detail is amazing but his real talent has emerged through his play-doh. He makes the people, creatures and things he sees on his videos. When he is finished, they look exactly like the ones he has copied, down to the finest detail. They have to be perfect for him to be satisfied and they are truly beautiful."

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## Federal Budget Priorities

Roy's story (see page 4) covers two key areas of action we'd like to see in this year's Federal Budget:

- A rise in the rate of payment for Carer Allowance. While we think a rise of at least \$20 pw is warranted, the incorporation of the one-off \$600 'bonus' as a regular yearly payment (equivalent to \$11.54 pw) would be greatly appreciated by families.
- An increase in the maximum rate of subsidy for nappies available through the Continence Aids and Assistance Scheme (CAAS) for those aged 16 and over (which would then also help to convince state/territory governments to increase continence assistance for children aged under 16). Also, families should not be adversely impacted by having to pay GST on continence products.

Our other priorities include:

- The need for federal leadership in solving the crisis in access to after-hours school and Vacation Care for families of teenagers with a disability.
- Improved Centerlink administration of the 63 days respite rule for Carer Allowance.
- Improved approach to eligibility and payment arrangements for Carer Payment.
- Federal leadership to develop a national solution for families of children with a disability who need access to a modified vehicle to transport their child.

The day after the 2005 Federal Budget, we'll be starting work on our priorities for the 2006 Budget. To get involved and contribute your ideas, contact AAFCD Co-ordinator, Helen Johnson on freecall 1800 222 660 or by email ([helenj@aaafd.org.au](mailto:helenj@aaafd.org.au)).

### Website Updates

Whether it's the latest news on the parliamentary progress of the Federal Disability Education Standards (which will have an impact in all states/territories later this year) or links to government consultations like the In-Home (Child Care) Review, keep an eye on our website [www.aaafd.org.au](http://www.aaafd.org.au) for the latest updates.

# AAFCD State/Territory Representatives

**ACT**  
Cheryl Patrick

**NT**  
Bruce Young-Smith

**SA**  
Cale Dalton

**VIC**  
Barbara Alexander AO  
Jan De Witte

**NSW**  
Katrina Clark  
Kylie Ramstadius

**QLD**  
Leonie McKnight

**TAS**  
Dianne Fuglsang

**WA**  
Clara Harris

Contact Helen Johnson, AAFCD Co-ordinator, on freecall 1800 222 660 to be put in contact with your AAFCD State/Territory Representative.

## Stretching that Rubber Band



Stuart Shaw

"One would be to increase the nappy amount from \$500 to \$1,000 dollars per year. The amount I am getting is only lasting half a year. Being on a Carer's Pension, I struggle to pay the other \$600 for the second half of the year."

### MP Challenge

"I challenge the Prime Minister, the Treasurer and all other federal MPs to read Roy's story and then look me, Roy (and the rest of us) in the eye and say that we don't deserve an increase in the Carer Allowance, and for those children requiring nappies on a permanent basis, some extra help with the cost of nappies."

Helen Johnson  
AAFCD Co-ordinator

Let me start by telling you my son's name: Stuart John Shaw. He is thirteen years old and his condition is cerebral palsy, quadriplegia, epilepsy and he has a slight vision problem. I want to tell you about some of the day-to-day problems my ex-wife and I have to face. We have both had Stuart in full care and now we share care.

Stuart cannot walk or talk but he can walk in a walker. He has medicine twice a day for his epilepsy. We have to mash his food because he cannot chew properly. He has a reflux problem so we have to have bibs for him and we change him at least three times a day. There is a lot of washing and keeping him dry. Stuart puts everything in his mouth (that's how he senses things) so you have to watch what he gets into.

Stuart has to wear nappies and we need to change him about three to four times a day. If he gets to his poos before you do, he eats it and makes a mess of his clothes, the sheets, the walls and himself, so that means more cleaning and washing. We have a shower chair to wash him but it's not easy.

There are a lot of other issues such as picking him up from his wheelchair, his pusher and off the floor. It's hard work, without much help. There's a lot of stress in this life of changing, washing, cleaning and schooling. Then we have to show a brave face to our family and friends, who haven't got a clue as to why you're not quite yourself or why you don't feel like going out much!

But saying all that, we have plenty of lovely moments as well. Stuart is a happy lad. I know in my heart that he appreciates everything that we do for him. But there are a few things that would bring a bit more happiness to our world.

One, would be to increase the nappy amount from \$500 to \$1,000 dollars per year. The amount I am getting is only lasting

half a year. Being on a Carer's Pension, I struggle to pay the other \$600 for the second half of the year. With the money saved, I could take my son to happier places like the movies, swimming or horse-riding, and I would have more money for petrol to take him to these places.

Second, would be to increase the funding for cars and vehicles, housing and other aids that people with disabilities need, especially when they're growing up. The government could offer very low, fixed interest rate loans or package deals for when people with disabilities turn sixteen and over, so that they can get a house and car of their choice at a low, fixed interest rate.

Third, would be for people with disabilities to have very cheap access to recreational places such as the movies, swimming, gyms, horse-riding etc. You could have a card for seasonal or annual payment. This area is where I think my son misses out because it costs \$27 every time I go to the movies, \$10 to go swimming, \$20 for horse-riding and on it goes. This is for Stuart, my daughter and myself. At these prices, it makes it hard for Stuart to have fun.

When you're on a pension, you can only stretch that rubber band so much. These three things would make a big difference to us, and to anybody else in the same boat.

Roy Shaw, Whyalla Norrie, SA



Australian Association for  
Families of Children with Disability

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