

National NoticeBoard

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

Budget Credit

Whatever else you might have thought about this year's federal budget, we were very pleased to see (for the second year in a row) the contribution of parents and carers recognised in the Treasurer's budget speech, and backed up with a \$600 'bonus' payment for all Carer Allowance recipients and \$1,000 for all Carer Payment recipients.

We spend a fair bit of our time (quite rightly!) criticising federal and state/territory governments for not doing enough to support families of children with a disability. But we are also always prepared to give credit where credit is due.

The Treasurer, Mr Costello, the Minister for Family and Community Services, Kay Patterson, and everyone else associated with federal budget decision-making, are to be commended for committing additional funds for Carer Allowance and Carer Payment.

These bonus payments provide 'real money' that is of direct and immediate assistance to families of children with a disability, and they are much appreciated.

As in 2004, the 2005 payments are listed as 'one-off'. It is disappointing there is no guarantee they will continue in future years.

While the government has demonstrated a willingness to make the payments yearly, the political reality is that they go into the 'pot of possibilities' for 2006, in competition with other budget proposals. Also, if there is an economic downturn (and less money being collected in taxes) the bonus payments might be vulnerable to being considered unaffordable in the budget context.

One of our key advocacy tasks over the next year is to make sure all federal government decision-makers are fully aware of the value of the bonus payments to families of children with a disability.

You might like to contribute by writing and telling us what you have used your bonus payments for, what difference it has made to you and your family, and your thoughts on

Recognising the contribution of carers

"Carer Payment is available to a person on low income providing constant care for a person with a disability or a child with a profound disability. Carer Allowance is available where a person provides daily care to a person with a disability.

In recognition of the contribution these people make, tonight I announce as I did last Budget an additional \$1,000 to be paid to those 90,000 people on the Carer Payment and an additional \$600 payment to those 300,000 receiving Carer Allowance. These are people helping those who cannot look after themselves. We value the work they do. They deserve this recognition. It will cost \$317 million in this year. It will not affect the carer's social security entitlements and it is tax-free."

Excerpt from the Treasurer's 2005 Budget Speech

why the bonus payments (or an equivalent rise in fortnightly payments) needs to be guaranteed for future years.

In 2004, as part of our discussions about the need for a rise in Carer Allowance, we published a sample of family contributions on the topic of 'What would you spend an extra \$20 per week on?' (see Edition 13, May 2004).

These 'real-life' contributions were a very effective way of educating decision-makers about the value of a rise in the rate of Carer Allowance for families.

With your help, we need to keep doing this sort of education to make sure that families of children with a disability are kept on the priority list for the 2006 budget.

Michael Gourlay, CEO, Association for Children with a Disability and Helen Johnson, AAFCD Co-ordinator

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Senator the Hon Kay Patterson, Minister for Family and Community Services

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AAFCD

Australian Association for
Families of Children with Disability

A Ghost in Her Wake

Sometimes I see a ghost in my daughter's wake. The ghost doesn't merely appear—I put her there.

Sometimes on Sunday mornings I lie awake (in spring it can be pre-dawn) and I wait for my daughter's arrival to herald the start of our day together. As she hurls the door open noisily and waddles awkwardly towards the bed muttering 'Where are we going? Where are we going?' and signing 'food' repeatedly with insistent jabs to her chin, I look behind her and conjure up specific images of her ghost.

Images of a lithe, slender, yet muscular body, well-proportioned and beautifully coordinated, tip-toeing softly toward me; images of her sitting gently on the edge of the bed with precisely measured and directed movements so as to avoid sitting on my legs or feet under the covers; images of her quiet whispers—so as not to wake her father—of last night's party or yesterday's fight with her boyfriend or tomorrow's exam.

The ghost is always beautiful; she has the same sleek dark hair, long, past her shoulders; the same deep brown eyes, the same olive skin and full mouth. But her eyes are always focussed and they're bright and full of expression; and her mouth utters bubbly, complicated sentences—sentences with meaning, words that respond to my questions with thought and deliberation.

I have lots of stored images and memories to draw on to make the ghost seem real. I take these images from memories of her older sisters' lives; they've left me with precise knowledge of what should really be happening to my 17-year-old daughter who is about to embark on her final year of school.

There'd be thick books and folders and uniforms to buy; there'd be endless hours spent chatting on the phone; there'd be the constant beep-beep of texting friends on her mobile if she had one (her sisters didn't at that age but I suspect she would); there'd be parties and boys, risks and adventures that I'd hope she'd avoid but probably wouldn't—but she'd survive anyway.

She'd be chatty and funny and say 'awesome' a lot and put the word 'like' into every second sentence. She'd keep her



Di Fuglsang (centre back) with family (clockwise from right) Claire, Christopher, Madeleine, Bridget and Isobel

room messy, we'd argue about the loud music and the phone bill, but she'd surround us with her youth and enthusiasm in our late middle age.

I think about the specifics of her growing up here in this house, which is much smaller and closer to town than the one where her sisters spent their adolescence. I think about the mealtimes, of her help, under sufferance, in the kitchen—perhaps she would cook the odd meal or two. I think of her relationship with her three older sisters and what she may have brought to their lives—possibly less suffering, yet less wisdom than is the reality.

There'd be casual hugs and quick pecks to my cheek as she leaves the house with some boy who is besotted with her looks and her cheery manner. I'd fling some last minute reminder about tidying her chaotic room or perhaps I'd just tell the boy not to bring her home late.

Sometimes I try to console myself for the loss of the ghost with imaginings of her as a drop-out or I see her as a teenage mother with me babysitting for hours while she hangs out with young friends, some of whom have rings in their tongues.

Sometimes when I'm trying to make this imaginary life far worse than my real one, I see the ghost with a drug problem and I'm the supportive mother by her side at the rehab clinic, where she's staying for a while.

But I can never quite sustain this image for long, it seems an unlikely one—I always

"The ghost is always beautiful; she has the same sleek dark hair, long, past her shoulders; the same deep brown eyes, the same olive skin and full mouth."

"I think of her relationship with her three older sisters and what she may have brought to their lives—possibly less suffering, yet less wisdom than is the reality."

come back to the pretty, dark girl with the flawless skin and the laughter she brings to our lives.

The moments when I manipulate the ghost leave me feeling sad and deflated for a while, but not for long, perhaps 10 minutes at the most, although sometimes the ghost's lure is seductive and hard to move from.

It's a well-established, slightly obsessive torture I've practiced for years; a sort of test to see if I can still get in touch with the feelings of lost dreams, the 'what might have beens'. I wonder why I do it, I think it's just a habit now. Every time I'm amazed at the depth of feeling it brings, but also how quickly those feelings dissipate as I discard the images.

Obviously the ghost is someone I will never know, and so I must eventually turn my attention to the real person, the flesh and blood, the gestures and needs of the daughter who is here with us now.

When I delve a bit further, which is usually quite easy to do these days, I recognise there are lots of things to celebrate about her today: the joy of new achievements, new words, new milestones; the lessons learned from living with her; the satisfaction gained from surviving the journey thus far; the new friendship emerging with her as her understanding of spoken language takes a developmental 'spurt' and her behaviour becomes proportionally calmer and more 'normal'; and of course all the people I would never have met had it not been for her.

The ghost, I'm sure, would never have taught me such lessons so quickly, nor have shown me lives of such courageous and tenacious families; nor have introduced me to so many compassionate, warm and wise people from such varied walks of life.

Despite all this though, I still wish so often that I knew her—the ghost, that is.

Dianne Fuglsang, Battery Point, Tasmania

New Tasmania AAFCD Rep

A big thank-you to Di Fuglsang who has recently stepped down from her role as the AAFCD representative in Tasmania. We wish Di all the best as she pursues some of her other passions in life.

We also extend a warm welcome to the new AAFCD representative in Tasmania, Manuel Duharte, who is also the Executive Director of the Association for Children with a Disability Tas Inc.

The dignity of my son

Many years ago, I overheard a person being asked what to buy their 4-year-old child for her birthday. The response was, "Anything for a six month old baby would do." I decided that day that I would not keep my son as a baby. I had the power to allow him to grow and develop in age appropriate ways. This has not always been easy but I believe the dignity of my son is at stake.

In the March edition of NNB one word that was constantly used was the word 'nappies'. I guess that this is one of the areas I can also help to develop my son's dignity. As a 14-year-old, my son does not wear nappies.

I can remember hearing for the first time 'incontinence garments' and thought what

huge words to get my tongue around. Yet over the years, I believe I do not know how much my son understands and how he feels if I lower him to the age of a baby.

In all the other areas of my son's life I am trying to help him develop in age appropriate ways so why not in the area of incontinence. Other words that can be used are 'disposable pants' or 'pants'. Another reason I like to use adult words is because when my son is involved in a mainstream program it is embarrassing for him to have his 'nappies changed'. His acceptance is so important and it covers every area of his life and development—even his disposable pants!

Christine McDonald, Victoria

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
AAFCD Co-ordinator
590 Orrong Road
Armadale, Vic, 3143 or email
(helenj@aafcd.org.au).

Continence Funding, including Continence Aids and Assistance Scheme (CAAS)

Firstly, I'd like to thank Christine for the above contribution. As somebody who has been guilty of using the term nappies inappropriately, I appreciate Christine's perspective and will attempt to ensure that all our references to continence products are age appropriate in the future. And this is very timely because we are gearing up for a major campaign to increase the level of subsidy available through the federal Continence Aids and Assistance Scheme (CAAS) for those aged 16 and over (and the state/territory program for children under 16). For more information, and to contribute your perspective on unmet needs regarding continence assistance, contact Helen Johnson, AAFCD Co-ordinator on 1800 222 660 or by email helenj@aafcd.org.au.

Michael Gourlay, CEO, Association for Children with a Disability (Vic)



AAFCD Membership—Strength Together!

AAFCD Membership is FREE for families! Members receive our bi-monthly National NoticeBoard magazine. If you are not already a member of AAFCD, simply fill out the Membership Form on the AAFCD pamphlet and post it to us using our Reply Paid address (no postage stamp required). You can also join over the phone by ringing our freecall number 1800 222 660, or go online to www.aafcd.org.au and complete the online Membership Form. For more information, and to be put in contact with your state/territory representative, contact Helen Johnson, AAFCD Co-ordinator, on freecall 1800 222 660.



In 2005, the Make-A-Wish Foundation hopes to grant 600 wishes to children throughout Australia.

In order to reach this target, the Foundation is encouraging all people who know eligible children to bring the possibility of a granted wish to the attention of their families.

For more information phone the Make-A-Wish Foundation National Office on 1800 032 260 or see www.makeawish.org.au.

Make-A-Wish Foundation of Australia

Do you know any children who have a life-threatening illness? They might be eligible to receive a special wish from the Make-A-Wish Foundation.

The basic philosophy of the Make-A-Wish Foundation is to grant children (under 18 years of age) with a life-threatening illness their cherished wish, providing magic and joy for them and precious memories for their family. Since Make-A-Wish began in Australia in 1985, it has granted more than 4,000 wishes to Australian children. Their wishes tend to fall into one of four categories:

- I wish to be...*a princess, firefighter, police officer etc
- I wish to go...*Dream World, the snow, Disneyland etc
- I wish to meet my...*favourite popstar, television or sports star etc
- I wish to have a...*cubby house, pool, computer etc

To qualify for a wish from Make-A-Wish, the child must have, in the opinion of their medical specialist, a life-threatening illness. The child must be under 18 years of age at the time of application. Families of children of 4 years and under may apply for a 'wish box'. Provision of a wish box will not prevent the child receiving a wish when older if they are still eligible.

Make-A-Wish provides wishes to children who are non-verbal. In this case, they work out wishes with family members as well as the child. Make-A-Wish Australia is the only wish granting organisation in Australia that grants international travel wishes.

In 2005, the Foundation hopes to grant 600 wishes to children throughout Australia. In order to reach this target, the Foundation is encouraging all people who know eligible children to bring the possibility of a granted wish to the attention of their families. They will need to complete a brief application form and enable the wish granters to meet with their child, but beyond that, there is no further obligation required of them.

For an application form or more information, contact the Make-A-Wish Foundation National Office on 1800 032 260 or see www.makeawish.org.au.

Walk a Mile in My Shoes, National Day of Action, 13 September, 2005

In response to overwhelming support after the airing of 'The Hidden Army' on 4 Corners (also see Edition 19, May 2005), a group of family carers have organised a national day of action in Canberra to invite politicians to 'walk a mile' in their shoes.

Families who care for a child or young adult with a disability are invited to meet on the lawns of Parliament House and leave a pair of their own shoes, tagged with their age, the number of years they have cared and details about the person they care for.

For more details and to register contact: Felicity 07 3359 9131 (Queensland); Nell 02 9477 2288 (New South Wales); Jean 03 5127 1904 (Victoria); Carole 08 9398 6329 (Western Australia); Dignity for Disabled (D4D) at email@dignity4disabled.com.au (South Australia); a contact person is yet to be confirmed for the Northern Territory, Australian Capital Territory and Tasmania but families can email walkamile@optusnet.com.au.



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