

**April 2006**  
**Issue 2**

## **Backdating of Carer Allowance**

The Senate is currently considering a Bill that will reduce the period for which a person can back-claim Carer Allowance from 12 months to 12 weeks. The National Welfare Rights Network (NWRN) has prepared a briefing note about this issue. See below.

The proposal appears unnecessarily mean spirited and will disadvantage many families that are already struggling.

NWRN are asking for organisations that oppose the Bill to contact them so that they can use your names in their campaign against the Bill. To do this, you can email Gerard Thomas [gerardt@welfarerights.org.au](mailto:gerardt@welfarerights.org.au) or phone him on (02) 8217 9909. If you are prepared to pursue the issue more (ie, contact Senators etc) let him know when you email/call.

### **Family Assistance, Social Security and Veteran's Affairs Legislation Amendment (2005 Budget and Other Measures) Bill 2006.**

#### **Schedule 6 - Backdating of Carer Allowance Provisions**

Carer Allowance is an income supplement that is paid to someone who provides daily care to a person with a disability or significant medical condition, and the care is provided in the home of the care receiver or the carer.

Carer Allowance is non-means tested and paid at the rate of \$94.70 per fortnight. In 2005, 334,085 persons were in receipt of Carer Allowance.

In the 2005-06 Federal Budget the Government announced changes to the backdating provisions of Carer Allowance allowing it to be backdated for only 12 weeks prior to a claim being lodged.

Currently, Carer Allowance for carers of a child with a disability and who is under 16, can be backdated for up to 52 weeks. In addition, Carer Allowance for carers of an adult with a disability can be backdated for up to 26 weeks if the disability is due to the acute onset of an illness.

The point of having such extensive backdating provisions is that Carer Allowance has such a low profile in the community – and a lot of people do not know that it is not income or asset tested.

People are providing care for family members and often do not know about it for a long period after they have started care.

The other reason that it is unfair to restrict the backdating provisions for Carer Allowance (adult) is that it is only paid after an acute onset of an illness.

In our experience, when someone has become sick and needs care on a daily basis, the last thing on your mind is to contact Centrelink.

The National Welfare Rights Network is concerned that there is no sound reason for this change in the explanatory memorandum which accompanies this Bill. We also point out that this mean spirited measure comes only a year after the Government was forced to extend eligibility for Carer Allowance (adult), allowing it to be paid to people who did not live with the person being cared for.

The change will, in some cases, halve the amount of back pay to which a person is entitled. This could mean that a person who is providing a valuable caring role for a child with a serious disability could be worse off to the tune of \$1,894 if these provisions are passed by Parliament. This equates to 20 fortnights of Carer Allowance.

The beneficial backdating of Carer Allowance provisions was there to recognise that people who were caring for family members with severe disabilities are often unaware of what their entitlements are, and are often busy providing hands on support, rather than contacting Centrelink.

The explanatory memorandum. puts the savings from this provision at \$34.7 million in \$2006-07, saving almost \$100 million over three years.

Please Note: Topic for the next issue is “**Challenging and Problem Behaviours**”  
Please send all contributions to the editors [edit@a4.org.au](mailto:edit@a4.org.au) for consideration.

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## Convenor's message

Dear A4 member,

Our editors have focussed this Update on respite. And the next Update is about challenging or problem behaviours.

By telling us in advance, they are challenging us to provide our own material. Please look at the topics that are coming. Perhaps you have a particular interest in or issue with one of them, or wrote something on the subject before (maybe a university assignment). How about sharing your thoughts and ideas with the rest of us.

Normally I don't say much about respite because respite is typically seen as a carer issue. And my focus is advocacy for people with autism rather than carers.

There are a number of carer organisations whose role is to support and advocate for carers. So I tend to leave carer and respite issues to them. But I encourage A4 members who want to advocate on behalf of carers and issues relating to ASD to do so under the A4 banner.

Perhaps I avoid talking about respite because I want to be seen as strong and self-sufficient. While I am reluctant to admit I need it, respite is an essential service for my family.

The community needs to look after its carers, and it wants carers to look after themselves. Generally, family carers are the cheapest and may be the best option for supporting people with ASD (if you know of relevant research, I'd be interested to hear about it). From the government's perspective, family carers are cheap and effective.

Autism often appears as a distinct category in recent publications from the Australian Institute of Health and Welfare (AIHW) relating to disability services and people with a disability. This welcome change follows our asking that ASD be treated as a distinct disability. We expect this distinct reporting for ASD will lead to better understanding of outcomes and needs.

In the last A4 Update, I mentioned two "key initiatives" from the NSW Early Childhood Intervention Coordination Program (ECICP): documents entitled *Best Practice Standards for Early Intervention* or *Recommended Practices in Family Centred Early Intervention*. I spoke with DADHC and they said these documents are not available in electronic form. To get a copy, ask DADHC.

The ECICP has been in operation for some time. Since many children with autism have complex needs and could benefit from coordinated services, I am interested to know what advice and insights the ECICP has for children with autism and their families. I am interested to know whether the ECICP identified any services gaps that were/are particularly relevant to children with ASD, and if so what they did about them. A DADHC official wants me to put my questions in writing. I will let you know how this goes.

Regards, Bob Buckley [15/3/2006]

## The Apex Foundation - Trust for Autism

The purpose of The Apex Foundation Trust for Autism is to sponsor research into the incidence, cause, diagnosis, prevention, treatment and the principles of behaviour of children who may be diagnosed as having Autism, Pervasive Developmental Disorder, Asperger Syndrome or other related disorders. It may also sponsor research into the social, educational and recreational requirements of children with an Autism Spectrum Disorder.

The funds available for research grants each year represent interest on the corpus of The Apex Foundation Trust for Autism. In 2005 and 2006, funds from the Autism Council of Australia were used to maintain the level of previous grants whilst The Apex Foundation undertook a

strategic review of its Trust Funds. The Autism Council of Australia Research Fund comprises proceeds from the sale of Thomas and Friends products in Australia in 2002.

The Trust for Autism was established in the late 1960's from funds raised by a Walk Around Australia for Autism, organised by Apex members. Since then over \$500,000 has been disbursed by the Trust, representing the interest earned on the corpus. The Autism Council of Australia Professional Committee is responsible for evaluating applications and recommending the grants to be made. For the past 14 years Autism Victoria has voluntarily managed the application process on behalf of the Autism Council of Australia.

Application forms are either posted or emailed to the cumulative database in June of each year, with submissions due by July 31st. This database includes the Research and Grants office at most Australian tertiary institutions, as well as all previous applicants and expressions of interest.

In 2005, ten applications were received and after much robust discussion the professional committee recommended that two grants be made. The successful applicants were:

- Dr Umesh Sharma, Faculty of Education, Monash University, *Empowering parents of children with Autism to manage disruptive behaviour. (\$5,589)*
- Dr Robyn Young, School of Psychology, Flinders University, *A two year follow up of the children of the university's Early Intervention Research Program. (\$6,411)*

For more information contact Autism Council of Australia, Amanda Golding, via phone 03 9885 0533, PO BOX 235, ASHBURTON VIC 3147 or email [admin@autismvictoria.org.au](mailto:admin@autismvictoria.org.au)

## Raindrops and Respite

I have a confession to make. I'm no martyr. In fact, there are days when the absolute last thing I want to do is be a parent - shhh, don't tell anyone!

Whilst I love my kids to bits, the reality of having a special needs child is that it's exhausting, hard work. You have to think ten steps ahead at all times. You can't do as many things together as a family. Cinemas are out, restaurants that don't include cookies on the menu are a no-go and a 'real' holiday—one where you go a bit further afield than Grandma's—seem impossible.

Before long, the wonderful 'challenged-but-enjoying-it' attitude you've worked so hard to show the world begins to crack. Suddenly you're raising your voice to the kids. You're hard-pressed to find the enthusiasm to eat a sandwich, let alone prepare dinner for the family. Housework is a distant memory.

*My husband once told me about a fantastic analogy for stress which I'll share with you now:*  
**Imagine your life as a bucket, and the everyday stresses as the raindrops which fill it.**

Every day - even if you don't realise it - the raindrops add up. Some days a lot - perhaps Junior had one of his world famous meltdowns in the middle of the shopping centre - and some days hardly anything at all. Suddenly you come to the realisation your bucket is almost full. You're almost at your limit. Even just one extra drop and you're going to overflow.

***This is where respite is worth its weight in gold.***

Initially I was apprehensive about the whole idea of respite care. I didn't much like the idea that I would be handing my children over to the care of a relative 'stranger', nor the fact that I was used to our son's unique personality and worried about the poor respite worker being lumped with his difficult behaviour. I needn't have worried. Our workers - we have two very lovely ladies - each came for a 'meet and greet' before our first real respite night, and each one

bonded with all three of our children quickly. A huge plus for us was also the fact that all workers carry a senior first aid certificate and usually some other qualifications such as a manual handling certificate.

Some people choose to use their allocated respite hours to run errands which they might not otherwise be able to fit in around caring for a loved one 24-7. My husband and I are lucky in a way - there have always been various combinations of childcare, kindy and now school to give us that break during the day, but what we were lacking was time alone in the evenings, specifically to go out and do those 'date-type' activities not normally possible with small children.

I once read a statistic that said parents of a special needs child have a much higher risk of divorce than the national average of about one in two marriages. Being married to a police officer myself, I was also interested to learn that police marriages are also in the higher risk group. Statistically speaking, the odds are stacked against us. We feel it's important to set aside this time alone for the benefit of our marriage.

Think of it as 'emptying your bucket'.

*Karen Smart - Karen Smart has been a stay-at-home mum since the birth of her son Jake, who is now seven. Jake was diagnosed 'moderately autistic' in April 2002.*

## **System has foiled Kate**

19/03/2006 - Sun Herald News

In Balmain lives a 10-year-old boy so autistic he can't communicate, can't bear to be touched, can't even take himself to the toilet. His mother, Kate, who is caring for him and his brother alone, can't control him and he is always running away.

Kate is so exhausted her hair is falling out and worried friends have arranged for her to go to a depression clinic.

"She's close to completely cracking up and needing 24-hour care herself," says her friend and lawyer Karen Oakley. "She said to me, 'I don't want to be another Daniela Dawes.'" Dawes was the Sydney mother who killed her autistic 10-year-old son, Jason, in 2003.

Deinstitutionalisation was supposed to allow children such as Liam to be cared for at home, with long-term community support. But that support has never been adequately funded or managed.

Oakley says that when Kate hit crisis point recently, funding for Liam's respite care became a buck-passing exercise between the Department of Ageing, Disability and Home Care and the Department of Community Services.

The heroes of this story are the staff at (non-government) St Anthony's Family Care, Croydon, who pleaded with their board last week to fund Liam's care full-time for two weeks while his mother rests.

On Friday, a spokesman for Disability Services Minister John Della Bosca said Liam would get six more weeks of care in another facility.

But St Anthony's chief executive Diane Campbell says: "Even if she gets care this time, I'm not sure how she's going to cope with him long term ... the aim is to keep [children] with their family, but Kate needs to know that when she does call for help people are going to take her seriously."

## **Government creates autism crises**

*Letter to the Editor, Sun-Herald*



Your story (System has foiled Kate, Sun-Herald 19/3, p15) about Kate's situation is another example of how government fails children with autism and their families. This government learned nothing from Jason Dawes' life and tragic death: it ignores the substantial needs of its most vulnerable citizens and their families. The Minister's plan makes Kate's life a series of crises.

Where is the treatment that teaches Kate's son to communicate, to dress himself, to use a bathroom, etc.? What is being done to reduce the burden of caring, both for Kate and her successor(s) in the caring role?

Effective programs for autism are intense and autism specific. But governments contribute very little to families who want to treat their child's autism and minimise the burden of autism on the community.

The cost to the community of government not funding treatment for autism is enormous. In this situation Kate cannot do her best for her other son. How much does that cost the community? All credible analyses show not treating autism and failing to support families properly is very bad economics.

Readers should keep this in mind whenever politicians mention economic responsibility.

Bob Buckley, *Convenor, Autism Aspergers Advocacy Australia (A4)*

## Lesson is how to wait

*Letter to the Editor, Sun-Herald*

YOUR story "System has foiled Kate" (The Sun-Herald, March 19) is another example of how the poor level of disability services in NSW is to blame for the current respite crisis.

While the minister's offer for respite will be of great help to Kate, what happens in six months? Where is the government support for teaching Kate's son basic self-help skills? Disability services is more than respite - it must be about treatment and prevention.

In the US, children with autism receive 40-plus hours of intensive behavioural intervention as soon as they are diagnosed. While they may never be cured, they are learning skills that enable them to function in and contribute to their local communities. In NSW, however, families receive little more than long waiting lists and, if we are lucky, two hours of intervention a week. When will the NSW Government learn that the cost to the community of not funding the effective treatment of autism is enormous?

Sam Lo Ricco, *Director, Autism Behavioural Intervention NSW, Lindfield*

## Message from John Ryan MLC

### **Shadow Minister for Disability Services, NSW Parliament**

I need your help to press for a better deal for people with disability.

Recently I received information from the NSW Government that last year 956 people applied to fill accommodation vacancies in the disability support system, and only 104 people were successful, meaning that in the order of 90 percent of the applicants were rejected.

I released this information to the media and on Saturday 18 March 2006, an article appeared in the Sydney Morning Herald publishing these figures and the stories of two families who like you, described how the shortage of accommodation and respite affected their lives.

<http://www.smh.com.au/news/national/faces-of-despair-as-calls-for-help-go-unanswered/2006/03/17/1142582520916.html>

I am keen to make contact with other families who have also suffered from the lack of supported accommodation for people with disability so that I can raise this issue in the NSW

Parliament and give the matter more public attention as a means of ensuring that your concerns feature as prominently as possible in the debate that occurs in the lead up to the 2007 State Election. I believe that your concerns have not received the attention that they deserve and politicians will only recognise them if we make them a prominent part of public debate.

While I am able to read about your stories in last years "End the Silence Report", I cannot raise your concerns unless I have had a short conversation with you to confirm that your situation has not changed since the Report was published in October 2005.

I would be grateful if you could make contact with my office with your contact details (phone number, email and/or street address.) so that I can talk to you and familiarise myself with your circumstances, and then consult you about the best way to advance your cause with the Minister for Disability Services and the Department of Ageing Disability and Home Care.

Feel free to either email, write or phone me using the details below. Anyone wanting to reduce the cost of the phone bill can call me first and request me to call them back.

Yours sincerely, John Ryan MLC, *Shadow Minister for Disability Services, NSW Parliament*,  
Macquarie Street SYDNEY NSW 2000  
Phone 0418 203 729 (mobile), 02 92302894 (Office) and [John.Ryan@parliament.nsw.gov.au](mailto:John.Ryan@parliament.nsw.gov.au)

## Upcoming Events FYI

Date	Type	For more information
14-21 May 2006	<b>National Autism Week</b>	
19-22 May 2006 Sydney NSW	<b>Mindd International Forum on Children</b> Integrative Solutions for Autism, ADD, Learning Delay & Chronic Illness <b>Friday 19 May</b> The Art and Science of Dietary Intervention. Lectures and cooking classes <b>Saturday 20 May</b> Integrative Diagnosis and Treatment. Mindding Our Children Benefit Dinner <b>Sunday 21 May</b> Integrative Diagnosis and Treatment <b>Monday 22 May</b> Physician's Training with Defeat Autism Now! Workshop for GPs and professionals.	<b>Mindd International Forum QLD</b> <a href="http://www.mindd.org">www.mindd.org</a> <a href="mailto:info@mindd.org">info@mindd.org</a>  <i>Please note for Parents and Carers from out of town Mindd can organise accommodation with member families or offer discounted hotel rates. All are welcome to the benefit dinner.</i>
17-18 October 2006 Cairns QLD	<b>Seminar</b> <b>Target Audience:</b> All involved in social skills programming including Teachers, Special Educators, Therapists, Psychologists, Guidance Officers and Counsellors <b>Presenters:</b> Lynda Melville and Kathryn Fordyce	<b>Autism QLD Inc</b> <a href="http://www.autismqld.com.au">www.autismqld.com.au</a>  <b>Phone:</b> 3273 0000 <b>Fax:</b> 3273 8306
14-16 April 2007 (Note: next year)	<b>Biennial National Autism Conference</b> Gold Coast QLD	<b>Autism QLD Inc</b> <a href="http://www.autismqld.com.au">www.autismqld.com.au</a>

## Letters / Emails

Please send letters to [edit@a4.org.au](mailto:edit@a4.org.au). Letters sent to the editor may be published unless they are clearly marked "not for publication". Normally, they will appear with your full name and state unless you mark them clearly "anonymous" or "first name only".

### **Tanya - respite** [19/3/06]

I have a 7yo with a dx of AS and a 4 1/2 yo with autism. We live on the South Coast of NSW and access respite through interchange. Every second Saturday the boys attend Saturplay where they meet at the autistic school and then break up in groups and go on what we refer to as "adventures". Because my boy's abilities differ they never do anything together but that's ok as I think they also need a break from each other. They do things such as picnics, movies, bowling, train rides, playcentres, swimming etc. Pretty much anything that the carers can think of. It's great also as the kids are learning independence as well as appropriate behaviour in public. We have been accessing it since Dec 2004 and initially my younger son would scream when he was dropped off and picked up but now he can't get there quick enough. The carers that run Saturplay are fantastic, patient and have a huge understanding of ASDs which makes it easier. When my 7yo started to resist going I sat down with the coordinator and once we worked out the problem she had a chat to him, said the right things and now all is good again. They amaze me with their patience and the fact that some of them work 5 days at the autistic school and then give up their Saturday to give us respite shows me how much they care.

We also get 4hrs a month that I can use in the home, to go out, get my hair done, go out with my husband etc. I'm having a bit more trouble organising that but only because there is not so many carers available. I'm planning to use it to spend time with my 7yo which he misses out on because of the 4yo's demands.

Overall we're very happy and haven't really had any problems to speak of.

### **Name withheld by request** [20/2/06]

I read with interest your February issue regarding ASD adult services. I am a parent of a young adult with ASD and find it extremely difficult in dealing with the education department i.e. schools, here in SA. It seems parents are to be satisfied with the standard school reports given to all students, with little extra information as to how the young person is coping etc. I am not sure if it is because of ignorance about ASD or lack of training, but it is very poor service in my opinion. Although entitled to I have had no NCP discussions in years, subjects that the young person as requested have simply been dropped without notification with a seemingly "we know best" attitude, even though the young person enjoyed and received good marks for it. As for any respite, school time is it, and that's only when not contacted regularly to come and collect the young person for whatever reason. I dread to think what opportunities or lack of opportunities they will face as an adult.

### **Jim and Cheryl - Our story** [15/2/06]

This is one of the hardest things I have ever had to write - probably second to my son's eulogy. Why is it so hard? Probably because I want people to understand and support both of us. And yet it is so hard for me to understand, let alone explain it to others. It has been an incredible rollercoaster of emotions since we met three and a half years ago that I feel so exhausted and washed out.

The main issue for us as a couple is that my partner's special interest is other women. 'Jim' (who has been diagnosed with Aspergers) has said to me he has more enthusiasm for other women than me, he gets distracted and high being with other women, I have been around for too long because he gets excited by other women, and he needs to make other women feel special. He also believes he has no control over his reaction to other women. However, he also says he loves me.

When we are at home alone we have a very caring and supportive relationship. Bring another woman into the picture or when he is out there in the world he becomes like a different



person. His family think of him as a shy person and with me at home he is quiet, reserved, and affectionate but he becomes outgoing, charming, flirtatious, full of interest when with another woman. The closeness we have has disintegrated during that time.

We have been to a number of professionals and had advice ranging from trying to give my partner tips on caring in a relationship, turning his back to women, getting relationship counselling, Cognitive Behavioural therapy, CBT won't work, and hypnotherapy. He has started on medication so the sexual excitement has reduced but his need or reaction to women is still there, with the profound change in his behaviour.

The most understanding support was from a female psychologist who deals with Aspergers and sexuality, who used CBT. While it seemed to have some effect at the time for my partner it was, with his best intentions, impossible for him to maintain that awareness or change.

So now I am trying to look after my own mental health and find the answers and professional help to help us in our relationship. My partner says he wants to be able to deal with women in a normal way, but it is all too hard and nobody can help him.

I am determined and pray that I can.

### ***Time to Shine*** [7/3/06]

This is just a cool story. An autistic boy who had helped all year by getting the team water is given a chance to play on the last game of the season at the end of the game. What happens then surprises everyone. <http://www.compused.com/directlink/1257/>

### ***Respite contacts***

[www.civ.org.au/uploadedFiles/1142466251853-6393.pdf](http://www.civ.org.au/uploadedFiles/1142466251853-6393.pdf)

### ***Letter to the Age***

The NSW government is probably holding it's collective breath that the Bracks government will slip through its proposed disability bill this week, which will remove the onus of disability services from government and send it hurtling back onto families.

NSW loves Victoria's bad disability policy, it sets a precedent which we are seemingly happy to follow.

Narelle Ricketson, Balmoral Street, Waitara, NSW

### **A4 Contacts**

A4 is a grassroots organisation. All A4 activity, such as publishing the Updates (newsletters), is done by volunteers. Please understand that A4 volunteers may have no training or qualifications for their various roles. They do the best they can for people with ASD, their families and associates. A4 welcomes assistance and constructive criticism.

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