

Australian Senate  
Community Affairs  
Legislation Committee  
Parliament House  
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10 March 2006

Dear Committee Members

RE: Family Assistance, Social Security and Veterans' Affairs Legislation Amendment  
(2005 Budget and Other Measures) Bill 2006

On behalf of our 6000+ members across Australia, most of whom are parents of children with a disability, our Association is writing to your Committee to STRONGLY oppose the recommended changes in Carers Allowance – Child to *'standardising the backdating provisions for Carer Allowance to allow a maximum backdating period of 12 weeks before the claim is lodged, whether the Carer is caring for an Adult or a Child'*.

For the various reasons outlined below, we strongly believe, that the current 52 week backdating provision for Carers Allowance - Child is appropriate and should not be changed.

As a parent of a 12 year old boy with a severe intellectual, medical and physical disability, who is non-verbal, incontinent, has various medical complications, is physically challenged and relies on me to support him 24 hours a day, 7 days a week, 52 weeks of every year, I am taking a step back in time to consider what our circumstances were in relation to applying for and receiving a Carers Allowance.

I recall my son's birth, and on day two, being rushed to a Melbourne Hospital and life saving surgery being performed on my son when he was only 3 days old. Before this surgery we were 'surprisingly' handed a photo of Ben attached to, and surrounded by, life saving medical equipment. We asked the reason for the photo and were informed that due to the enormity of our son's complications, he may not survive, and that this photo would be something for us to remember him by. Can you imagine the overwhelming grief and trauma that this situation brought to our lives?

I recall the many lonely weeks we spent in hospital, 180km away from our home, family and friends. Whilst in hospital we were trained to perform various medical procedures on Ben which had to be applied by us in our own home. This was all so new to us and words cannot describe the fear and uncertainty that filled our hearts, body and soul every single day. There were also the numerous daily and overnight trips we were forced to make to visit many medical specialists both in our home town and back in Melbourne, to tend to Ben's medical emergencies and to determine our son's prognosis and diagnosis. Ben had over 10 surgical procedures for various medical complications before he was 3 years of age.

During this time we became extremely financially burdened, however we realised it was of greatest importance and a priority to do everything possible to support Ben. We were forced to purchase specialised equipment, medications, medical supplies and pay for ongoing medical & therapy services.

I cannot specifically recall how I learned of the Carers Allowance but I do remember it was well beyond 12 weeks after my son's birth. It was like living in a maze as no-body told us about entitlements or services that we were eligible for and when the time was right and I finally found the 'head space', I had to discover and research all this information myself.

When I finally did learn about and applied for the Carers Allowance and received a backdated payment, it was something that was very much appreciated and utilised to support Ben with his complicated and ongoing medical concerns.

Today life is still filled with ongoing medical appointments and he is now under the care of 20 various medical specialists at the Royal Children's Hospital. Like many families we are continually forced to purchase ongoing medications (some of which are not available on PBS), medical supplies and equipment to support Ben with his every day needs.

The Australian Association for Families of Children with Disability represents families of children with a disability covering any type of disability and across all areas of Australia. Our Association urges your Committee to make recommendations that the option for Carers Allowance – Child, remains available to be backdated for up to 52 weeks, as per existing arrangements.

Another issue that your Committee need to take into consideration is that many Australian families are on a waiting list for their child to have an assessment, in order to receive a diagnosis. Due to the system often being stretched to its capacity, assessments can often take many months and for some, in different areas across Australia, it can take years. Therefore, many parents are unable to apply for the Carers Allowance until they have had their child assessed. If your Committee chooses to make a recommendation that the option for Carers Allowance - Child should be cut to allow backdating to only a maximum of 12 weeks, then, in our view, it would be punishing and discriminating against families who, through no fault of their own, are unable to obtain appropriate disability assessments and/or diagnosis.

Also, your Committee needs to consider that many families (myself included) go through a process of 'denial' around the time of diagnosis as they do not want to believe that their child has a disability. Many families in this situation are clinging to hope that everything will be normal, the way they had hoped and planned it to be for their new family. The last thought in one's mind during this time, is to apply for a Carers Allowance. The experience of parents of children with a disability at this time is a type of grieving process. In my experience, and that of many other parents, eventually some form of acceptance of our child's disability does occur. This is when a parent can eventually recognise, and in some way, accept that their child does have a disability and therefore, disability related services and allowances, such as Carers Allowance, may be relevant for them and their family. For many families it is extremely expensive to support a child with a disability and there are many costs incurred whilst caring, both in terms of actual financial costs, emotional costs and also other unquantifiable costs such as reduced opportunities to do paid work. Once again, in my experience, and that of many other families across Australia, the up to 52 weeks of backdating for Carers Allowance – Child is a very welcome and necessary recognition of actual costs we have incurred in the previous year of caring for our child with a disability.

In summary, our view of the proposed cut back from a maximum of 52 weeks to a maximum of 12 weeks is encapsulated by the response of one of our parent members who said, the proposal is, "cruel and stingy".

We do not accept the argument put forward by the proposers of this Bill, that there is any confusion between backdating provisions for Carers Allowance - Child and Carers Allowance – Adult, for the same reason, we do not accept that there is any need or any rationale, based on real life family experiences, for any standardisation of backdating provision to occur across both Carers Allowance – Child and Carers Allowance – Adult.

Our Association is made up of parents of children with a disability who have real life experiences, including experiences of access to Centrelink and the Carers Allowance. We know from first hand experiences, that parents of children with a disability, once they discover their eligibility for Carers Allowance, are appreciative that the up to 52 weeks backdating, does recognise some of the actual costs they have incurred in the previous year, as well as providing some recognition and confirmation of the difficulties of their experiences during the early years of their child's diagnosis.

In addition to being 'cruel and stingy', if the government proceeds with this cut-back for Carers Allowance – Child from 52 weeks to a maximum of only 12 weeks, many families, their friends and extended family members will also consider this as cruel and heartless.

In finishing this submission, we would now like to share with you a perspective from some of our parent members who are currently in receipt of Carers Allowance – Child. All names and addresses have been supplied and can be provided upon request. Further, we could provide you with many more examples of real life parent experiences from across Australia if required.

A Victorian Parent:

“Lewis was 2y.o. before we applied and we had a diagnosis of Cerebral Palsy at 9 months but it took me that long to begin to accept it. Denial is a complex and valuable defence mechanism that needs to be considered for families in these situations. Back payment for up to one year should be available. Anything less is cruel and stingy.”

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A New South Wales Parent:

“I know from my own experience that one of the last things on a parent's mind when struggling with the diagnosis and care of a child who is found to have a disability is the extent to which that may make the parent eligible for some kind of government assistance.

This fact coupled with the lack of information made available to parents with children who are newly diagnosed from medics, therapists and elsewhere, means that parents should be given as much leeway as possible in claiming where they are eligible to do so.

Indeed, to be totally fair to the parent, the payment should be back-dated to the date it can be shown by a medical report that the child's condition satisfies the criteria.”

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A New South Wales Parent:

“I am the primary carer of my son, Alexander, who has a severe intellectual disability. I was forced to take a redundancy from work 10 years ago to dedicate myself to his full time care.

I am on a Disability Support Payment myself (and was receiving a Parenting payment at the time I would have applied for the Carers Allowance). I can tell you all about the financial constraints of life on a pension, whilst trying to meet the huge costs of caring for a person with a disability (eg, not even all medications are on the PBS.....)”

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A Northern Territory Parent:

“In my personal experience my daughter was 1 month off 3 y o before doctors were able to ascertain her disability of Cerebral Palsy. Prior to that, there were a myriad of appointments/tests etc. that we had to go through as well as we tried all sorts of aids and facilities trying to get a finger on the problem. We were too worried about trying to determine our daughter’s problem without going thru the social security support system discovery problem which by the way is a secret minefield in itself to a new initiate.

We were gratefully surprised when we were granted 12 months back pay but found this did provide some compensation for equipment, medical supplies etc.

We live in Darwin, how could someone who lives here, let alone the more remote communities expect to uncover the secrets of the social security system in a timely fashion?

I would hope that you and your colleagues take this all into account when you consider the bill.”

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Once again, on behalf of our many members across Australia, our Association would like to re-iterate the importance of the current backdating provision for Carers Allowance – Child, to remain unchanged. From our parent’s point of view, the current provisions are appropriate and working well. It’s a simple case of, ‘If it ain’t broke, don’t fix it!’

We would like to thank your Committee for giving our Association the opportunity to provide this submission and we are available to provide any further information if necessary.

Yours faithfully

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