

15 April 2009

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House Canberra ACT 2600

Dear Committee Secretary

**Submission: Social Security Legislation Amendment (Improved Support for Carers) Bill
2009**

In consultations on NCID's submission to this Inquiry participants were angry that the Inquiry was taking place under a 'dishonest' pretext. The letter seeking submissions states:

The Committee has been requested to examine the provisions of the Bill to ensure that they adequately meet the needs of carers.

Any reading of the legislation clearly shows that this is not the case and does not even come close, so why ask a question that can only be answered in the negative and about which very little if anything will be done? "Families have better things to do with their time, why waste it in such a patronising way?"

Yes the legislation does, potentially, expand the number of families that will qualify for the Carers Payment and the other changes will also benefit some families. All these changes are welcome.

But to pretend that the intention was (or is) to 'adequately meet the needs of carers' is dishonest as "it is just not going to happen".

After a session a mother rang me to read out her calendar for the previous month, it was a 'bad' month but as she explained 'bad' months happen and frequently. She has 2 primary school children one with a 'moderate' disability and from the examples in the Explanatory Memorandum to this legislation the family would not qualify for the Carer Payment. In the previous month she had 2 medical appointments, 1 optometrist appointments, 1 multidisciplinary assessment, 3 therapy sessions, 3 school meetings with teacher, 1 meeting with the regional education advisor and a massage for herself! As she said, "there is no way she could do all these and be a reliable employee".

During a telephone interview a mother responded to the question - Do you think many people would take up the Carer Payment if it were available to all families in receipt of the Carer Allowance? – by saying "most if not all". Her explanation was that (sic) mothers want the best for their children and for a child with a disability that takes time. Time at school to ensure that they have the support they need and that teachers and aides are aware of their child's needs (it often means helping out at school). Time to arrange and attend medical and therapy appointments at times that are convenient for the Dr and therapists not the family. Time to do sport and other activities so that their children keep healthy and are part of their community. "Time, time, time ... there is never enough."

The only father to participate in the consultation made particular comment on the example on p 8 of the Explanatory Memorandum, Reginald and his son Morey. To summarise his comments:

1. the example presents a simplistic picture that does not reflect any situation that he is aware of and ignores (patronises) the role that parents play.
2. Just because Morey has an aide at school does not mean that the Reginald does not need to be involved in his schooling, particularly where behaviour is concerned. It is not uncommon for kids to be suspended for behaviour, so parents have to be very watchful to ensure that any behaviour is picked up quickly and appropriately dealt with before it escalates. Also, it is important to ensure that behaviour programmes are in place to ensure that Morey's behaviour difficulties decrease over time; this means meetings with psychologist, school counselors and the co-ordination of a behaviour plan across home and school (who will do this? Reginald)

3. At a young age Morey needing a moderate level of assistance in dressing, bathing and feeding may not sound like much but what happens when he gets to high school. Morey's behaviour will hinder his ability to learn, it is therefore important that he not be assisted but taught and this means time with an OT and the carrying out of a plan to ensure independence not dependence on Reginald for ever. This takes a lot of effort and time. The use of the expression 'not substantially greater than a child of the same age' demonstrates a complete ignorance of what it actually means to raise a child with even a moderate disability.
4. Reginald will struggle because he want to do the best he can for his son, he will juggle a job and his son's many needs and he will feel guilty that he can not do either to the best of his ability.
5. Morey will struggle and become more dependent on his father and community for his financial support
6. Reginald is prepared to sacrifice income so that his son has a future, the response from politicians and bureaucrats is – you are on your own we do not care!

The response from workers in the field is that if the Senate (and House of Representatives) wanted to 'adequately meet the needs of carers' then it should listen to real families and respond to their needs. The Senate must not rely on examples that are misleading and devaluing of the role that families play in supporting their sons and daughters to have good lives.

All the participants were adamant that the language surrounding the Carer Payment has to change, it is misleading the Australian Community to suggest that:

the "Carer Payment provides income support to people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation" p. 2 Explanatory Memorandum.

It only provides support to some; and it is disrespectful (and dishonest) to families to state:

“(t)he qualification criteria and assessment process for carer payment for the care provided to children with disability or a medical condition will be changed to provide a fairer and more equitable process, based on the level of care required, rather than the rigid medical criteria

used currently.” Outline to Explanatory Memorandum.

Given the examples in the Explanatory Memorandum the system will be changed and yes more families will benefit but the system will not be fairer or equitable to all families living with disability.

It is appreciated that the comments in this submission are not very helpful. There is a strong consensus that this legislation does not and was never meant to “adequately meet the needs of carers”.

NCID requests that at some time the Senate takes the time to consider what really must change to ‘ensure that the needs of families (carers) are adequately met’. Exception was taken to the use of these words in the request for submissions letter though only in the context of this Bill.

It is recognized that members of the Senate have over the years demonstrated a genuine interest in the needs of families (carers). What is needed is an understanding of why parents make sacrifices to ensure that their children have a good future, and what support the Australian Parliament and community can give them.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Mark Pattison', with a large, stylized flourish at the end.

Mark Pattison
Executive Director