

Submission to the Inquiry into better support for carers

AOC 4/8/08

Submitted by:
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Submission No. 1138
(Inq into better support for carers)

Key Issues:

- Recognition of different in home after school care options to enable working families of severely disabled children to access the child care rebate.
- Recognition of the increased cost of living for families with a severely disabled family member in determining means testing for accessing assistance and support
- Provision of support to prevent family crisis and breakdown
- Consideration of allowing expenditure on equipment and aids (e.g. wheelchairs, assistive devices etc) to be tax deductible
- Allowing exemptions of the luxury vehicle tax and/ or GST on vehicles for families with a severely disabled member

Background

I am the parent of two children, the youngest of which is 5 years old and severely disabled with a rare neurogenetic syndrome called Angelman Syndrome. Its a real doozy of a syndrome with severe intellectual disability, no speech, seizures, sleep disturbances, he cannot walk yet, isn't toilet trained and will need constant care for the rest of his life.

My husband and I need to work to manage the financial burden both now and in the future - our super will need to support three people, not just two. Where we have been able to successfully find employers who can accommodate are roles as carers (often tired, flexibility to take time off to visit specialists, care for our son when he has seizures etc), we find that the biggest hurdle to us managing our work commitments is that a system designed to support health able bodied children is not flexible enough to accommodate the needs of disabled children.

Comment

1. In order to maintain our work commitments, like most parents we need to utilise after school care. However, the school does not have an after school or vacation care facility. With the nature of his disability, even if this was available, the nature of his syndrome necessitates a quite environment to prevent overstimulation that would result in him staying awake all night. Due to his level of disability, we qualify for support for in home care however this is where the problems arise. To access a carer so that we can qualify for the childcare rebate, we must source a carer from a registered provider which is typically the home day care scheme organisations. Like all industries, they are experiencing a skills shortage and despite being on several organisation's waiting lists for over six months, the prospect of a carer becoming available is unlikely. Issues which impact this is that we are only seeking two to three hours a day and this is not sufficient work for many of the carers. We have been able to find our own carers who are typically uni students working for other disabled service providers who are fully qualified with first aid and blue cards etc but to have them register with the home day care schemes would require them to pay over \$400 each to pay insurance costs with those organisations (even though we have a household workers compensation policy that we pay for). Given the relatively low pay rates and minimal hours, this is obviously not attractive to carers that we can source so we are left on the waiting list and the gloomy prospects. Therefore we face the very real likelihood that one of us will need to either worked reduced hours or give up work completely if this isn't possible with our employers.

FaHCSIA staff were very helpful when I rang to investigate this issue but clarified that there was no capacity at the moment to assist us and that the system had no capacity to accommodate the issues carers of disabled children face. We could have our own carer as a "registered" carer and receive the child care benefit which would be a minimal reduction in the

hourly rate but to qualify as an "approved" carer, we would need have our carer go through an approved provider. I understand the requirement for these sorts of checks and balances as the government cannot be subsidising nannies and other sorts of private in home arrangements where after school care is an option. However, that option isn't available for us and for many other carers that want to/need to be employed and have severely disabled children. My child qualifies for a healthcare card and carer allowance. His disability is severe enough to be recognised as a box to be ticked on the the relevant application form for those benefits. Therefore through a fairly simple process of cross checking with this system it could be verified that we are genuine carers of a severely disabled child and not exploiting the benefit. We would then be able to engage suitable carers, cover the risk through our own workers compensation scheme and receive the benefit of the child care rebate.

We would not be creating an onerous burden on the taxpayer and would be able to participate in the workforce which is good for both our family and the economy. . We are not seeking any additional system that would assist us, just a few extra amendments to an existing mechanism available to carers of non disabled children.

This is a simple idea but one that could have significant benefit for the affected families. It would also demonstrate a commitment to the challenges of carers and make it that little bit easier for us to help ourselves. I am not one of the countries most best and brightest who convened for the recent 2020 summit - more one of the most tired and haggard, but I want to be out there looking after my family and can see a simple way for the government bureaucracy to assist me and other families in our position.

2. Means testing is a frustrating process for carers of severely disabled children. The impact of the cost of a severely disabled child affects all aspects of our life. A spoon for him to learn feeding is \$20, a specially designed bowl is \$20, the out of pocket expenses for a wheelchair is \$1500, a special toilet seat is \$450. We struggle to manage these costs even on a "above average" income. We can't go on low budget holidays for our family – camping is not an option. All dimensions of our lifestyle for our whole family are impacted so the cost of living is significantly higher and this needs to be considered when using income as a criterion to assess a family's need for assistance and support.
3. The policies at state and government level are biased towards families that are in crisis or have already broken down (which is obviously a priority) however why does my family have to reach that point to get assistance? It was easier for me to source assistance for post natal depression that it is to seek assistance for the pressures of being a carer of a severely disabled child. Preventative care for the carers and family are critical. Too many families are being destroyed and broken down with the consequences impacting multiple generations.
4. The ability to claim the expenses that we incur specifically for Finn should be considered for inclusion as a tax deduction. Currently, the less we earn the more assistance we would get. Help us to keep working and supporting our own family by providing the incentive through the taxation process.
5. Once any disabled child grown beyond the smallest of wheelchairs, most families are faced with purchasing a large vehicle. Regardless of the fuel costs, economic or environmental efficiency, a large vehicle is required to enable the support equipment to fit into the vehicle and enable the family to access the community along with basic services. The luxury vehicle tax will impact those families for whom a larger vehicle is not a luxury but a necessity. Also, the current taxation system allows for a disabled person to have a GST free benefit for the purchase or upgrade of a vehicle if they are using the vehicle to access employment. This issue affects carers as well, we have to transport our child to enable us to maintain our employment as in home care is certainly not an option (see point 1). This benefit should be extended to carers of severely disabled family member where the family is the primary carer.

Thank you for any consideration you can give these ideas. Please help us, help ourselves with the ideas presented above. Currently, there is potentially greater incentive for us to have a parent leave the workforce and be a greater burden on the welfare system.