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Submission No. 957

(Inq into better support for carers)

Carer Inquiry Submission

Australian Government Standing Committee on Family, Community, Housing and Youth

My name is David and I am the Father of two children aged 8 and 5, both of whom have a disability, Jack and Ben have multiple disabilities and very high support and health care needs. The financial and practical assistance currently provided by both the State and Federal Government is woefully inadequate and pales in comparison to support offered in other developed countries.

My wife and I both care for Jack and Ben, I work full-time however my wife is unable to work due to Jack and Ben's care demands, Jack is often absent from school due to frequent and prolonged illness. We are a single income family by necessity not choice, we - like many other families - have a mortgage to pay, petrol and food are increasing in price and we are finding it increasingly difficult to manage on one wage. Jack and Ben have many additional expenses such as medical expenses, medication, special equipment and food - to name just a few.

I find it very difficult to understand why the **threshold for the Carer Payment is set so low (\$65k) when the threshold for other payments is between \$110k and \$150k.** We receive very little in way of assistance as my median wage (approx. \$60k) is deemed too high to warrant adequate assistance. The fact that we have two children with a disability - not one - isn't even considered, we incur double the hardship and financial cost however the threshold remains the same for us as a family with one child with a disability. \$65k is deemed a high enough wage not to warrant any assistance for a family caring for a disabled child yet \$150k is deemed a decent wage for other families, this is unfair and an example of the inequality and inequity evident within the system.

We provide 24/7 high support for Jack and Ben, they require full assistance with EVERY aspect of daily life, it is all consuming. We love Jack and Ben dearly however there is no denying the fact that providing full time care for two little children who will remain as dependent as newborn babies, probably forever, is completely exhausting - both physically and mentally. We have at times almost given up. We receive little more financial assistance as a family with a child who has asthma or ADHD (and is on the Carer Allowance). Why aren't families who have one parent who is unable to work because of their caring role considered and supported?

Support services offered by the State Government have greatly declined in the past couple of years, Jack and Ben rarely receive any therapy now and we have absolutely no say whatsoever in the services they do receive. Last week my wife argued the case with Jack's Speech Therapist when told she was going to close down Jack's Speech Therapy service, my wife was more or less told it was closing and she had no say in this whatsoever. The service closed despite my wife stressing how much Jack needed this service - it seems the area is so chronically under-funded that these services operate on a rationing basis as opposed to on an as-needed, individualised basis. Jack's individual needs weren't even considered. This is just an example of how such services are lacking, it has been over a year since Jack and Ben saw a Physiotherapist. We are about to start seeing a therapist privately at a cost of \$140 per hour, out of desperation. This will sink us further into debt but what choice do we have? There is great need for a new, more autonomous way of funding these services that would empower and give more control for families to be able to choose appropriate services for their child. It's about time parents decided what was appropriate and best for their child as opposed to a therapist who has had limited interaction with the child. Services are dictatorial and totalitarian, they are also chronically and acutely underfunded. Services lord it over families and insinuate that you are lucky to be receiving any service at all. The way services treat families needs to undergo drastic change.

The Rudd Government need to improve financial support for families providing such a high level of care for their children, it is unfair that families such as ours should have to live in poverty, we live in a lower socio-economic area with a variety of social problems, it is not a nice area to bring up children and we would never choose to live here however we cannot afford to live anywhere else. There is currently a huge demarcation line between families who have a child with a disability and those who don't, we have no choices available to us - we must rely on one income and that's it. The Government needs to create a system of equality and fairness where having a child with a disability does not automatically relegate one to a life of poverty. Increasing the threshold for the Carer Payment would be a good starting point so families such as ours on a basic single wage can have access to some support. Maybe staggering the Carer Allowance would also be a sensible approach - where the payment is different categories of disability, the more severe the disability the higher support needed so the higher the payment.

A **Superannuation scheme** for Carers is much needed, Carers spend much of their lives caring for a loved one only to approach retirement age with the prospect of continued poverty. Other help for Carer's could include lower income tax - where the number of dependents is taken into consideration when paying income tax then being a Carer could also be given consideration to increase the **threshold for tax**. It is unfortunate that in the last budget tax cuts were given - the budget surplus could have really been put to good use on social policy and supports for our most vulnerable members of society. I believe that a society (and Government) can be judged by how it treats it's most vulnerable members - what a sad indictment on our society and successive Governments that this issue has been so neglected for so long.

Thankyou for the opportunity to provide this submission.

My contact details are : David