

Productivity Commission

My Submission has been constructed from personal experience and from the knowledge of others in similar situations with disabled children. I am happy to discuss any topic surrounding disability care in the community

In this I quote "child" and this could fit for young adults through to elderly disabled situations also.

Wheelchair Transport

Something needs to be done to assist people obtain vehicles suitable for transporting their loved ones that are confined to a wheelchair,

Most of the time a rough vehicle that needs work might cost around \$10,000 plus work required to make the vehicle reliably safe and roadworthy, to get a nice vehicle might cost \$15,000 to \$50,000 in the public market place and this is impossible for so many families.

I believe that self provided transport for one's family should be a basic requirement, Especially when it comes to a family with disabilities, this is so important for a sense of normality and social inclusion.

I had to leave my work to care for my daughter and some weeks we can't even go shopping, how is it possible to then purchase a vehicle around the 15 to \$20,000. How is it possible to even go on a local holiday for a weekend or just a simple drive in the country without a vehicle, the child then becomes confined to the home residence apart from compulsory trips requiring an access taxi, then you have to book it early and often wait around when it's time to come home and let's not talk about having to wait for a taxi when the weather is rough being stormy or incredibly hot, and the appointments that you can be made late for waiting for a taxi when the appointment takes months to get in to.

To be as close to a normal family as possible having your own transport is a basic requirement that the majority cannot afford and if they manage it they end up in allot of debt which consumes money that should be going towards the basic living costs as well as the extra expenses due to the disability.

This could be done by offering very low to no interest loans, it could also be subsidised by the government to lower the cost to the family. Council and government vehicles could be offered to families on a list rather than putting them through an auction situation where most families are not able to afford the vehicle and this is where the government could reduce the price of the vehicle and have a loan structure for these vehicles to families that fit the criteria. This would then provide most families with the means to acquire a suitable vehicle with a good maintenance history to ensure safety and reliability

Excellent tax breaks could be offered to businesses who sponsor a disabled child by making monthly payments for a suitable vehicle for a family with a disabled child

Electricity

Electricity is a huge bill for almost every person in society, so it's as no surprise to know that many families with disabled children often have higher needs for electricity which of course produces a larger bill at the end of the term, many families are on close to survival money if they are unable to work so a larger electricity bill is something that just makes life harder and creates more stress in the family home which multiplies if the family are restricted to the residence most of the time.

Recently I have heard of many grants being offered to people that have decided to and could actually afford to install solar panels for their mains supply and also hot water.

This I find to be a great plan but the problem with this situation is the people that need it the most simply could not afford to get it done to start with.

I believe that it is desperately needed and would show outstanding initiative for a government to be installing solar systems in houses that have disabilities that fit a criteria including severe disability and able to show that an excess of electricity is required for the extra care involved caring for a disabled family member.

As an example we have to use our air conditioning system most of the year around to help our daughter to remain healthy and a comfortable temperature as she is unable to move around or change her situation if she is feeling to warm or cold. The doctors said that our daughter would spend half of her life in hospital due to illness and her inability to cope with simple colds to serious flu.

Through having the air con system running most of the year around our daughter has been in hospital about 3 times in 14 years. a few years ago the system broke down and my daughter came down sick over the following few days and went to hospital and took 2 to 3 weeks to recover.

This safety for our daughter costs us about \$600 a quarter on top of normal use which could easily be absorbed by a solar system for mains power leaving this money a quarter to go towards other expenses. But as we have minimal to no money left each week the idea of purchasing a solar system for the house is totally out of the question.

This makes it hard to understand how so many families with the desperate need for freeing up money and can't afford to buy a system get no help and a family that can afford to pay out \$5,000 to \$20,000 can get a very good rebate which has often been a sum amounting to a figure that could pay for a system for a disabled family. Something needs to be done and in helping disabled families it makes for a global impact on the green plan and helps so many people get much closer to being able to live a normal family life.

I have a family of 5 and we all have missed out on so much due to the low income and higher expenses surrounding our daughters disability.

Every family with a disabled member needs help

Government Payments and Work

The biggest problem for families with disabilities I believe is always going to be money,

For this problem I would suggest that the amount of money that can be earned from any form of work before government payments are effected should be doubled as a minimum. This would achieve a few positive outcomes, it would encourage people to get part time work if they are able to therefore raising moral within the family with a bit of extra income coming in to pay for all necessities.

An easy thing would be for government payments to have a large increase but that is understandably not practical for the country's economy so the next best thing would be to give these families a break and allow extra income.

It is not like they have chosen to be in this situation and people are not going to put themselves in this situation for an extra one to two hundred dollars.

This would also have to be restricted to a those families that fit a certain pre determined criteria.

Disability Equipment

For this one I haven't got the answer to where the money should come from but there is desperate need for more money to go to organisations like Novita for special equipment like wheelchairs, walkers, standing frames and many other devices that are in a high need.

My daughter if confined to a wheelchair and has a posture problem with her back and starting in her neck, she is on a waiting list for a new chair to be made for her to give her the support that's required to limit or slow the progression of her spinal disfigurement and provide allot more comfort,, she is on a waiting list which is suggested to be over 1 year, if you could only see her bounce and jar from the faults in the roads and wonder what a year of that is going to do to her as well as the stationary sitting in this chair. Equipment like this is something that should be able to be supplied within 2 months not minimally one year and it is all put down to funding.

If only many more people could see her innocent beautiful face and the discomfort she has to endure, nobody would want to leave it another day.

I see my problems throughout the disabled community, nothing I can say is new so I find it unbelievable that waiting lists are still so long.

Summary

I know that all problems cannot be fixed over night and that there is an economic situation to be considered, But when money can be given as a grant to sport, art, and just about anything else that can have a category I am sure that extra money can be streamlined to the disabled community.

No one likes to see innocent kids suffer in any way and the pain that we feel as parents having to watch this every single day and to be completely helpless to change things all we can do is scream out for assistance and now is the time for some screaming.

There are countless families out there doing it real tough and every little bit of relief that comes their way is met with open arms and gratitude.

For our loved ones we would do anything but for their care and extra needs it is much too often that we can do nothing but wait and endure their pain with them and watch helplessly.

What we really want for them is impossible but what we need for them is possible but it takes a few people in the right places to make a big difference in these people's lives.

Families with disabilities are some of the lowest income families in Australia and they live that life for one reason,,,, To look after their loved ones and keep them out of care facilities, because of this most families have a level of depression and this is so wrong, these families need help and they need it now.

Allot of carers have a feeling of no future life excitement because caring for their family member is so important and knowing that their loved one will most likely out live them they know they will most likely be caring for that person until they are not able to anymore at which time they are most likely unable to do most of what they desire.

I have never heard anyone that wants out of caring for them but they all need help

Also maybe some publicity in high schools for career choices in the disability care area as this is needed in all areas of specialised care and we need to be pushing this message and growing some more caring workers, maybe in high schools they should have work experience options for different places such as disability schools/centres and old aged facilities, these options should be put within reach to every student coming up to leaving school. Only a small percentage would advance in these areas but that could be a large increase in workers for these areas.

There also is a huge need for more respite options both in house and in specialised centres, in my family an increase of respite hours would be a huge help in allowing some extra normality in the lives of ours as parents.

Absolutely any way to save money or increase income in a family that is looking after a disabled family member full time is going to be a huge help.