

Submission No. 1200

(Inq into better support for carers)

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Trish

The Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family
Community of Housing and youth
P.O. box 6021
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CANBERRA ACT 2600

Hi,

I apologies for this submission being late, and I hope that it can still be accommodated in the report.

I am a mother of a thirteen year old girl who has multiple and severe disabilities and as such has very high support needs. Our overriding family goal is to keep Jordan at home with us. She is our daughter, no more or less special than every child and deserves to be an integral part of our daily life and live as ordinary a life as we can. However having said this we do not have an ordinary life. There are many limitations on our lives, stemming from the careers my husband and I can have, our social interactions, the car we drive, the home we live in, the place we live, the holidays we don't go on, the experiences we don't have. Jordan will not be an old lady, and every day I have with her is special, yet I spend so much of my time battling for equity and justice for our family that I lose precious time with her. Even today, instead of taking her out, I am writing this letter (so if the details are scant, I apologise, but we do have to factor in some fun), and experience has taught me that no matter how many letters I write, little will truly come of it. Yet I feel compelled to list at least some of the issues we have faced this year alone.

When our daughter Jordan was born and through her early years therapists would tell me that it was only going to get harder, and more expensive to care for Jordan, I don't think I really understood that until now, when every month it seems I face another Jordan issue and go into battle with another bureaucracy, the scary thing is that I don't know what next month's challenge will be.

1. After School and OOSH care for Children with Disabilities.

Until Jordan was twelve years old she attended a standard OOSH program with her brother. On turning twelve (and for no other reason – not health, funding, availability of a carer or a place) Jordan was expelled from the centre, in a very unceremonious and disrespectful way. Since that time (18months) we have been receiving “Critical Care” in our home for Jordan, whilst this actually suits us and meets Jordan’s needs for this time of day there is no guarantee week to week that this service will continue. My husband and I have once again restructured our work commitments to ensure we only need 3 hours per week for Jordan, but we can never be confident that the service will continue. Further the service is delivered in such a manner that all policies and protocols are centered on the employee giving the care, at the detriment to Jordan. Due to controls on lifting, carrying, pushing wheelchairs, hours worked; medication administration the care Jordan receives is way below the care she receives from us her family. The hours she spends with carers are full of limitations that ultimately compromise the care that she is given. We as parents are forced to accept these compromises so that we can continue in employment. We desperately need to be employed not only for our own well being, but to ensure a disposable income sufficient to meet Jordan’s needs. Even though we both hold middle management government positions and are in our mid forties none of our income goes to swimming pools or holidays like our friends our investment is in hoists, cars, care, medical services etc.

Our request here is that the government provide adequate and flexible support to families to meet the needs of the child who is the client. As Jordan’s pediatrician said, the person coming into the home should be “me” they should adopt our practices and culture.

2. Accessible Vehicles

This year we finally entered into finance to purchase an accessible vehicle for Jordan. This \$70,000.00 vehicle is not luxurious; it is a basic van with a hoist. Prior to purchasing this vehicle we owned our own vehicles and had access to a company car. Yet this investment was required so that we could transport Jordan in the last three years Jordan’s only excursions have been cut back to essential trips only, largely doctors appointments as we needed to stop and suction her when we traveled for more than fifteen minutes. We had to lift her in and out of the care and lift the wheelchair in and out of the car. This meant we never went anywhere as a family as one of us needed to stay at home with Jordan. Not to mention that Jordan had lost all her rights to participate. So we have sold our vehicles, cancelled our salary sacrifice lease and purchased this vehicle without ANY assistance.

Even charities will not help us. This is because we were lucky enough to benefit from someone else’s loss and purchased a vehicle with hoist. If we had purchased a vehicle and then modified (for the same cost and benefit) we would have at least

eligible for a donation from 'VARIETY – the children's Charity' or the 'Disability Trust', but by buying it as a 'job lot' we aren't eligible, and we had to pay \$700.00 more for transfer of the modified van, than for we would have if we just bought the van. Unfortunately we did not know all of this before we bought the vehicle, and even if we had we still would have gone this way as to stage the purchase and modification would just mean a greater health impact on Jordan.

Our request here is that the government at minimum should waive the \$700.00 transfer fee. Further modification of accessible vehicles for the disabled (average cost \$24,000.00) should be supported by the government.

3. Transfer of Incontinence Support from PADP to CAAS.

Until recently we received an allocation of nappies every six months from PADP, for an investment of \$100.00. Last year we became eligible for CAAS funding of \$470.00 p.a. this funding was directed towards all the other things that go with incontinence, such as blueies, creams, wipes, dressings, pads, disinfectant, gloves, gels, enemas, tubes, protections, washes etc. However this year we are now advised that whilst we will still have to pay PADP \$100.00 p.a. we are not eligible for nappies until November, effectively cutting in half the nappies we get from PADP for the \$100.00 and reducing the other products we can purchase.

PADP staff advises that this change has enabled them to meet more people's needs. It is not legitimate to say that you are meeting more people's needs by halving the service you provide.

Jordan has epilepsy, bronchectious, no independent movement, and limited cognitive ability, requires suctioning every 40 or so minutes (day and night), is on CPAP, is stoma fed every three hours and has two dislocated hips. She has 35 service providers. We have independently modified our home over the years at a cost of approximately \$140,000.00 for Jordan with a \$15,000.00 contribution from Home Mods. We are up to our third wheelchair, our sixth pair of AFOs, she has specialized seating, and lying and standing systems. She has a number of specialist communication systems, all purchased by us.

The therapist we work with are enthusiastic impressive professionals that are generally undervalued.

Our lives are not what we expected and we have been stretched to the limit at times. I could not possibly share with you all our challenges, day by day that we endure to keep Jordan healthy and enjoying life. However I know now that what we were told in the beginning is true. This will only get harder and more expensive, as a result we will all become more isolated from our peers and community. We have two children, and I realize that I do not spend my life fighting for Hugh to be included, to access the world around him. Why is it that my every day involves fighting for Jordan fraught with justification, reasoning

involving me in an emotional battle ground when all we really want is the opportunity to enjoy the life we have together.

Regards
Trish