Productivity Commission Submission

by Ronni Wood on behalf of my son Matthew

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As the mother and full-time carer of an eight year old child with severe and multiple disabilities and chronic complex health needs I know first hand just how broken our current disability system is. Our family is also unfortunate enough to live in South Australia, the state with the worst disability funding in Australia.

The past …

has been stressful and exhausting.

Matthew was born in Dec 2001 a week before his sisters 3rd birthday. It was not until after his difficult birth that his chromosomal abnormality was suspected (and later confirmed with tests) and 2 days later a major congenital heart defect diagnosed requiring open heart surgery in Melbourne at 10 weeks of age. And so began the nightmare of dealing with a health system not equipped or resourced to manage children with such complex needs. Shortly after I returned to the very well paid career of my choice Matthew required emergency surgery. Major complications resulted in an extended hospital stay, the loss of developmental milestones and the reality that Matthew was going to require round the clock nursing care on home oxygen for many, many months and his health would not be robust for the foreseeable future. There was no support on offer, so faced with no other choice than to resign from the job I loved, I took on this role. I have been unable to return to the paid workforce since due to my constant caring and advocacy role, Matthew's ill health and lack of support since this time. But despite forgoing over $60,000 in lost earnings per year the only compensation I receive is a Carers Allowance of $106.70 per fortnight ($2,774 pa or about 40c/hr). We have a mortgage based on being a two income family.

I hope the Productivity Commission investigate the possibility of paying all Carers unable to participate in paid employment the minimum wage and the funding for 4 weeks respite care per year so that we have the same basic rights as the lowest paid workers in this country.

Later an auto-immune deficiency and rare catastrophic form of epilepsy were added to Matthew's list of diagnoses. After enduring 4 years of unrelenting seizures, more than 20 hospitalisations and 12 surgeries we slowly emerged from under the cloud of the health system. It was now time to begin battle with disability services.

After an initial battle we had transferred from the organisation that my son was eligible for from birth to the only organisation that supports children with physical disabilities in SA and the first forest was destroyed in the name of bureaucracy. Due to his ill health and frequent hospitalisations he missed much of the Early Intervention to which he was entitled. There was a six month delay in obtaining his first wheelchair after the service provider received the funding, and it was only received 2 weeks prior to his commencing school shortly after his 6th birthday. A charity raised funds over a period of time to fund a walker for Matthew and so we naturally agreed to help with their fundraising efforts.

We had self funded most other equipment he had required up until this point. As the service provider undertook a major restructure at this time there was no therapy hand-over at this key transition time. Despite the fact Matthew could not walk, talk, feed himself, received hydration through a gastrostomy button and could not use the toilet, he did not have the maximum level of support at school. Nor did the other six very involved children in his class. And so began a protracted battle with the Dept of Education to obtain more funding beginning with the verification that my son in fact had a disability!! The second forest was felled. Despite the admirable efforts of the teacher she succumbed to stress and had several lengthy periods of sick leave before additional class-room support was obtained. Matthew received no government hands on therapy in this, his first year at school. Hence out of necessity we began self funding physiotherapy sessions once a week at school and once per fortnight at home. This became financially unsustainable for us so we approached the service provider about the possibility of releasing some of the government funds for us to purchase private therapy. We were told that there was no systemic process in place to allow the government to do this.

We could see the difference the physiotherapist was making to Matthew's development and his emerging walking skills and were desperate to maintain this therapy. We were fortunate to enlist the help of a charity with a proportion of the costs towards this therapy. However like all charities, this charity is also feeling the economic pinch and has been forced to cut the level of support provided.

After writing letters and advocating for self managed funding for over 2 years the South Australian Government announced the Phase One of the Self Managed Funding Project in November last year. I eagerly applied, made the usual barrage of phone calls, rejoiced at being made an offer, attended training and asked how much our current service provider would charge to provide the plans that I am told are required for Matthew to attend school.

The difference between the amount offered for therapy and the annual cost of the plans is $1400. Now anyone would realise that this is woefully inadequate to purchase a year's worth of therapy for a child learning to walk, communicate, use the toilet and feed himself who is reliant on the disability sector for therapy (he receives NO therapy services from the Education Department). Being dictated what I must purchase with these funds does not in my mind constitute self managed funding, and even more concerning is that this NGO stated that the package being offered (from NDA derived funds) was based on 50hours therapy per year at standard hourly rates, yet they would charge 1.6 times this hourly rate to provide reports required by the govt.

The ability for service providers (especially those with a monopoly over services such as for children with physical disabilities in South Australia) to charge Workcover rates rather than actual costs has a major implication for people attempting to participate in self managed funding and is something the Productivity Commission must investigate.

Last year after surviving on painkillers for my constant back pain we made the financially crippling decision to purchase a wheelchair accessible vehicle. Having a narrow driveway we had a limited choice of vehicles that we could accommodate. With no government advice available we undertook our own research and agreed that a Tarago met our requirements. We purchased a second hand vehicle and since the required modifications cannot be undertaken in South Australia arranged at our own cost to have the vehicle transported and modified in

Sydney. The fact these modifications are not even tax deductible added to the significant financial blow. The total cost of the vehicle, modifications and transport to and from Sydney was $78,000 and we still only have a second hand car. This is a huge sacrifice for a one income family with a mortgage. We successfully applied to the Variety Club for a grant of $10,000 towards these costs for which we are of course exceedingly grateful. And hence we agreed to be Ambassadors for their major fundraiser which entailed taking Matthew to an event hours after having a general anaesthetic and 5 teeth extracted and exposing our whole family to media attention. Is it right that people with a disability are dependent on a charity for the provision of basic human rights?

I know a family in South Australia who are considering selling their house to fund a wheelchair accessible vehicle.

I trust the Productivity Commission will look very closely at the implementation of a similar scheme to the successful Motability Scheme in operation in the UK where clients have the option to cash their motability allowance to lease a wheelchair accessible vehicle for NO cost.

http://www.motabilitycarscheme.co.uk/main.cfm?type=CHSW

The Present..

is a struggle.

We have very limited family support and no-one that will have Matthew overnight.

Because Matthew does not understand the concept of being quiet, and is extremely vocal, it is not possible to take him to the movies or to his sister's Music concerts etc. Hence in order to take my daughter to the movies or attend a Parent teacher interview we must rely on respite.

After exhausting all community options, countless phone calls and much begging last year we were granted 4 hours per week respite, which we can use Mon- Fri only, as well as 5 hours per month at weekend (but not Public Holidays) rates. I use the 4 hours per week to coach my daughter's hockey team and accumulate the hours when she does not have a match to use in the school holidays. We use the 5 hours per month to take her on an outing not possible with Matthew ie the beach. We are rarely able to go out as a couple. However, like all families who receive respite brokered through our service provider, our respite allocation is reviewed annually and we have been told to expect a reduction due to increasing rates and no corresponding increase in funding.

So I do not know whether I will be able to honour my commitment to coach my daughter's team after the end of the financial year.

As there is a very high demand for Vacation Care places for children with special needs at Matthew's school (due to having a special unit) Matthew is only able to access Vacation Care for a maximum of 2 days per week in the school holidays. Due to changes in the funding arrangements (see Attach 1) this cannot be confirmed until the required number of places is confirmed for typical children in the week prior to the holidays. This makes it very difficult to make commitments and the opportunity to obtain other (self funded) care arrangements challenging. It is also expensive respite and makes a trip to the movies with my other child an expensive outing.

There is a day program for special children run by a charity, but Matthew is too disabled for this program (must be ambulant and toilet trained). There is another program run by a different charity that would cater for Matthew's needs but currently is for indigenous children only and requires significant funding (not available to non-indigenous children)

At present HACC funding is assigned to service providers and often not accessible to those who need it. For example in South Australia some local councils provide significant amounts of respite to families caring for a child with a disability. But our council chooses to use their HACC funding for other purposes including washing windows for senior citizens.

I believe a more equitable system would be for (HACC) funding to be assigned to individuals on a needs basis enabling them to purchase respite services from a provider of their choice. This would enable families more flexibility and control and decrease the uncertainty and angst felt at this time every year.

Matthew is currently waitlisted for a Transfer Positioning Care Plan review (the one he has expired 3 months ago) and wheelchair seating review (as it has been 18 months since this was reviewed), speech therapy services and occupational therapy input was requested 18 months ago. We continue to self fund private physiotherapy sessions.

A true self managed funding system based on need would provide adequate funds to purchase hands on physiotherapy, speech and occupational therapy and give Matthew the opportunity to maximise his independence in his adult life resulting in reduced dependence on formal care in the future. Long term saving are available for governments through the use of early intervention which reduces the level of ongoing dependence on health and disability services in the future.

The Future..

Scares and depresses me.

I believe that Matthew should have the same right and choice as the rest of the community to live with people other than his parents in his adult life. I also believe that the government have a responsibility to provide this accommodation and support to enable Matthew to lead a decent life. He deserves this transition from the family home to be a planned one. And so does his sister. We know that we cannot continue to provide all his daily care and it is not fair that his sister and only sibling should be expected to either. Sadly we also know from current waiting lists that unless things change this will mean we must abandon Matthew in the future. This breaks my heart and makes me very angry. I also worry about the psychological impact on his sister. However, I know that in the current system if we do not abandon Matthew to get him into state care that we will never have the break from caring we so desperately need. And his sister will have the fear of the burden of being responsible for caring for him if something happens to her parents. She has sacrificed enough as a child growing up with such a profoundly disabled brother with so little support.

Like so many other parents of profoundly disabled children, some days the future looks so bleak that I dream Matthew will not wake up when I cannot continue caring for him. The present system which forces some parents in their 70s and 80s to continue caring unless they abandon their children has made parents of my generation feel this desperate.

We also know that the current South Australian model of Supported Accommodation in community houses will never suit Matthew. He will always need a higher level of medical support than this setting can competently provide.

We trust that a well funded National Disability Insurance Scheme will provide accommodation service providers with the guaranteed funds to build new supported accommodation models. We hope that these service providers will also have the assurance of funding to provide the appropriate level of support and choice of lifestyle options.

We believe this will include village style models with on-site swimming and other recreational activities as well as on-site medical and allied health professionals.

Our family's future relies on the outcomes of this Productivity Commission and the prevailing government's commitment to implementing and appropriately financing the recommendations.