

Disability Care and Support

Submission from Bridget Larsen (family carer)

PERSONAL RESPONSE

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DISABILITY CARE AND SUPPORT INQUIRY

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Outline

The Productivity's Commission Inquiry into Disability Care and Support is a long overdue, but welcome step towards addressing the needs of our other forgotten people. As our society has fragmented, the extended family unit and local community that once shared the care for people with disabilities has evaporated, leaving immediate families bearing the huge burden of caring for a child with a disability.

This was not a world that we understood until 3 years ago when our son was diagnosed with muscular dystrophy.

Our submission comprises -

- a brief outline of our son's disability, by way of background;
- two more creative pieces, by way of illustrating the emotional journey that we're on ("A Road Less Travelled") and the role that family carer's perform (a job ad); and
- a written response to some of the Key Questions posed in the Commission's paper.

If the Commission takes one point out of this submission, it is the urgent need to address respite care services through implementation of a skills attraction, training and retention strategies. Respite carers are at "the front line" every day. Their contribution to the economy is very significant – good respite care arrangements help clients stay out of institutions, minimize health costs and allow carers to continue to contribute to the economy, rather than becoming social security recipients themselves. They should be treated with the respect and remuneration that others on the front line are afforded.

I am happy to provide further information or oral evidence to the Commission if required.

My Son

By way of background, it may be useful for you to know a little about my son and family. My son, now 5, was diagnosed with Duchenne's muscular dystrophy (DMD) shortly after he turned 3 years old. DMD is a progressive neuromuscular disorder (1:3000 male births) that causes muscle wastage. By 9 years, my son will likely be in a manual wheelchair, by 14 he'll be in an electric wheelchair. There will be daily medication, occasional operations and hospitalization on the way. There is no cure – the average life expectancy is 18 years old. The condition can, and in my son's case is, also accompanied by mild developmental delays and ongoing behavioural difficulties.

My son is part of a Sydney neuromuscular clinic, so we travel interstate every 6 months for his appointments. He currently attends a local public primary school, where he receives good but very limited inclusion assistance. We also have a respite carer for 6 – 8 hours per week to assist after school - a regular program cannot provide the additional assistance he requires. And we have welcome, but limited voluntary assistance from one set of ageing grandparents and an elderly volunteer. The course of DMD is fairly predictable – over time, our son's needs will escalate and he will eventually require 24/7 care, including hourly assistance throughout the night. We are trying to provide a happy childhood for our affected son and his older brother as well as preparing now for all that is to come, financially, emotionally and physically.

My husband and I are both professionals with postgraduate qualifications. Since diagnosis, my husband has moved to a job that involves less travel and I have changed to a part time job with no travel to better accommodate my son's escalating needs. As a result, our incomes (and career prospects) are already reduced considerably. For nearly two years, we looked at different houses that will better suit our son's intense future requirements. We couldn't find anything suitable, nor was it practical to renovate where we were, so have now sold up our hard earned assets and pooled all our available resources to build a fully accessible house that is close to the schools and hospitals that we will inevitably need.

We are strong and capable people – we are informing and preparing ourselves for what is to come, but already exhausted by our son's needs and we still have such a long difficult road ahead.

A Road Less Travelled

Five years ago, my family was busy driving down the highway of life. Like most families, we had dreams of where we'd like to go and what we'd like to do along the way. We are a professional couple with good stable jobs, two young boys, a relatively small mortgage – we were driving down that highway pretty comfortably. We thought we knew where we were going and we certainly thought that we were well prepared to handle the odd unscheduled stop. That all changed in January 2008. Your son has Duchenne's muscular dystrophy, we were told. You'll be pulling off the highway now and going down that side road. And so we pulled off the highway and sat in the car at the beginning of a long rough road, not knowing where it went, how long it was, whether our car was up to it, whether there were services along the way, whether our driving skills were adequate. We had no time to pack for such a trip. Can I have a map, I asked. No, there's no map. Can I have a compass? No, you can have a bottle of water every 1000 kilometres, but otherwise, you're pretty much on your own.

Now that we're three years down that road, I can tell you that it's really slow and rough going. We are forced to drive slow enough now that we do appreciate the scenery more than we did on the highway. But there are really rough patches, the weather is harsh with some awful hurricanes and the number of cars crashed or burned out on the side of the road is alarming. I worry that our car isn't built for this and won't make the distance. I worry that there's only a few petrol stations out here and like most remote roads, they may not be open when we need them and will likely be very expensive. Sometimes, we meet others on our remote road – like all country folk, they're friendly, listen patiently to our story and give us some directions if they can.

I worry that the kids are fighting in the back as they get frustrated. My affected son wants to do all that his brother can, but as his condition progresses, he cannot. I worry that my older son won't manage the commute between our remote road and the highway, and that when the time comes to rejoin the highway, he might not fit in. I worry about losing contact with our friends who still travel on the highway – our scenery is so different and we don't always seem to have mobile coverage. I worry that I will run out of the patience, courage, humour and compassion that we need to get through. I worry that, as the road gets more difficult and requires a lot of night driving, that I will fall asleep at the wheel and crash the car, only to be found in some remote ditch years later. I worry that my co-driver and I will become strangers as we try to keep the car on the road, heading in the right direction. And when our remote road finally reconnects with the highway, I worry that we won't recognize it and will sit stunned on the verge for a long while, not being able to get up to speed with the traffic safely or at all. I worry a lot. I lose sleep and my heart hurts.

But hang on, this is just some metaphor. I don't live in a remote or rural area. I live in the capital of a democratic developed country, with a strong economy. Why then, do I feel so scared?

This submission sets out our experience as relatively new family carers. This is my story, but this story can happen to anyone at anytime. We need to be better prepared and supported in so many different ways. This submission sets out what we, as a family may need to survive our journey down our remote road. We will inevitably lose my son on the way, but I don't want his life or our journey to be in vain.

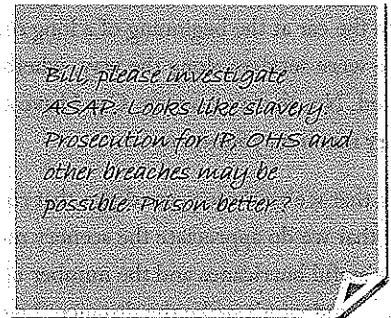
Challenging Role for a Dedicated Soul: Must Love Dragons

Executive/Personal Assistant

Our client is an energetic young person who does things a little differently. He now requires a full time PA to assist with all that his busy days bring, including education, personal care, nutrition, diary management and coordination of appropriate transportation to appointments, educational and recreational activities. This role will change from day to day and appeal to applicants that are adaptable and flexible.

To be considered for this role, you must have medical, nursing, physiotherapy and/or occupational therapy qualifications, or be able to demonstrate willingness and aptitude to learning in the role. Counselling or child psychology qualifications will also be highly regarded, as will a working knowledge of workplace safety, HR and discrimination laws, paleontology and mythology. Some training is available to suitable applicants (but must be completed within your own time at your own cost). You must also be able to demonstrate experience in -

- managing and coordinating complex communications with a diverse range of stakeholders;
- procurement of complex and simple equipment and services within a tight budget (your own);
- advocating your client's needs, identifying suitable programs and drafting successful grant applications;
- safely lifting up to 80kg on a daily basis; and
- successfully managing the daily needs of your client's immediate and extended family.



Superior oral and written communication and negotiation skills, high EQ and a sense of humour, are essential to your success.

Location: You will be based in a family friendly workplace. The role also offers significant domestic travel. Applicants must have a current driver's licence and own disability adapted car. Costs cannot be reimbursed.

This is a full time and long term position. Long and irregular hours are a pre-requisite (24/7/365). Ability to work effectively without sleep is essential. No overtime payable. Your contract will be secure (can be terminated only by the death of your client).

Remuneration Package: \$50 per week (less all family costs) plus annual bonus of \$600. Annual, sick, long service arrangements cannot be negotiated. No super.

Want to Apply?: No application or interview will be required. This role may choose you, anytime, anywhere.

Response to Commission's Key Questions

Part 3 of your paper makes some excellent points regarding the weaknesses of the current system – we can personally provide examples of many. We are delighted that the Productivity Commission appears to be tackling this difficult area in an informed manner.

We are not convinced that the UN Convention should be given too much weight in guiding policy in Australia. The issue is more fundamental – our society needs to embrace and care for its weak and different as if they were their own. Disability can happen to anyone, anytime. So can the caring duties imposed on those around people with disabilities. It is a risk of our being and as a society we need to collectively prepare for and manage that risk and support those who bear that burden.

Personally, I have to watch my son die. But I want to give him the best childhood we can. I owe it to my other family members not to lose myself in my son's needs – they have needs. And I do too, although I seem to forget what they are already. If we are not adequately supported as a family, as the PC rightly points out, we are all at risk of ending up tangled somewhere in the social security net and falling onto the lists of unpleasant statistics.

To put it another way, an employer who allowed their employee to care for someone that required hourly attention throughout the night for years on end without adequate respite would likely be gross negligent in knowingly allowing people without appropriate skills or qualifications to provide care for people with complex needs, be in breach of various work safety and OHS laws and driver fatigue legislation. Yet this is what carers are allowed to do. No, the government is not my employer, but when it comes to carers of high needs people, a stitch in time can definitely save nine in social and economic policy terms.

Eligibility

Who should be the key focus of a new scheme and how they may be practically and reliably identified?

I can speak only from our own personal experience, but those that bear the burden of people with long term and high needs, such as DMD, should certainly be eligible. In Denmark, there are 5 carers allocated for each DMD patient. Perhaps not a level of care sustainable in Australia, but here, we just have two exhausted parents desperately trying to hold it all together.

It is time consuming and emotionally harrowing having to recount my son's current and future needs time and again to various different service providers and agencies. I should not have to spend hours recounting his functional limitations, effectively pleading for help. So often have I felt like saying "Google it". Alternately, acknowledge that I am an expert in my son's needs and treat me as such, rather than the indignity of being treated like a dole bludger, in the most derogatory sense of the term. There are some conditions that have a predictable course without cure, such as DMD. In determining eligibility, perhaps we could all save time and resources by simply accepting that some conditions just qualify.

However, in determining needs, it is crucial to consider the other non negotiable responsibilities of associated family carers – their physical and mental health, financial well being, social interactions. We operate as a family unit and should be considered as such. For example, my son's care should not be permitted to adversely affect my relationship with my other son and my husband. Together we are strong, but alone we are weak. The statistics on carer depression, illness, mortality, divorce etc are all there.

And yes, it is also important to consider other factors, such as location, access to services etc. However, this is such a fluid picture in many cases that support for the future should not be "set" on without inbuilt flexibility. For example, my parents provide some care for my son, however, they are in the 70s and their ability to assist can and has been curtailed suddenly by ill health. Their goodwill should not preclude us from services for which we may otherwise be eligible.

Your paper asks whether the scheme should apply to new cases of disability or all people with existing disability. I found this surprising. Surely the scheme should apply to those in need – now – and not be determined by a time line in the sand. The latter approach would also require the management of the "old" scheme for existing cases and a "new" scheme for new cases. This seems utterly non sensical given the acknowledged difficulties with the one existing scheme.

Which groups are most in need of additional support and help ?

I cannot speak for others, but our interaction with the DMD community to date suggests that there are many who are struggling daily with indefinite and unresolved grief, the physical demands of caring for an incapacitated teenage boy, huge financial burdens, their own physical and mental health issues and little if any social interaction. This group have been so utterly consumed by their caring needs, compounded by fragmented "representative" groups, that they have not well articulated their needs. Our society is not good at asking for help and we often don't take the time to ask and listen to those who need it. Perhaps we should be starting there.

- ❖ Suggestion: Identify those affected by chronic progressive conditions - their interests have not been well articulated for a variety of reasons.

What kinds of services particularly need to be increased or created ?

We are only a short way into our journey with muscular dystrophy, so there is much ahead that I cannot address. However, in our experience of nearly three years' services, we have inevitably found both pleasant surprises and disappointingly poor services.

On the positive, early intervention from diagnosis was, I think, crucial in assisting both my son and ourselves prepare for the future. Our son learned key social, literacy and numeracy skills that have enabled him to be placed in a supported mainstream environment. An added bonus was the wonderful teachers who provided an informed and emotionally supportive environment for parents reeling with the grief and challenges of such a diagnosis. Both were immensely valuable and we would fully support their continuance.

The availability of experienced physiotherapy and occupational therapy services have also been very valuable, both in assisting our son maximize his dwindling capabilities but also in assisting us in developing suitable accommodation for his future (thereby minimizing the costs of retrofitting with modifications later on).

The local government school has been good in facilitating inclusion, but this is limited by resources and perhaps policy eg. we have to personally attend our son's weekly swimming lessons to assist him change into swimming gear because policy precludes such assistance. This is clearly very inconvenient for working parents who are desperately trying to shore up our financial resources to allow us to provide the intense care that he will require in the future.

- ❖ Suggestion: At diagnosis, early intervention, allied health and educational options should be discussed and initiated as early as possible. This helps both the child and the parents. This requires appropriate resourcing, but is also a matter of timely communication by experienced providers.

Access to GPs and pediatricians is difficult, with us often having to wait months for an appointment with the pediatrician. Our son's response to medication needs to be monitored and adjusted regularly to minimize serious side effects, so this is clearly a significant concern. At around \$180 per visit, with no recognition of the Health Care card, this is also a very expensive 20 minutes for monitoring medication.

- ❖ Suggestion: The skills shortage of GPs and pediatricians is well documented. Maintain the focus on initiatives to train, attract and retain these skills, but in the meantime, perhaps children with disabilities should receive some kind of "fast track". Additionally, pediatricians should be required to recognize the Health Care card.

Respite support has been reasonable for our current needs, but I am concerned about the extent to which this will increase as our son's needs escalate. Our son has built up a good rapport with his afternoon carer, but if she is ill or cannot coordinate her leave with our needs, we have no backup. The value of a trusted carer that understands their caree (and their family) is infinite. As parents, we cannot truly recharge if we are concerned about the level of care provided to our son. As employees, we cannot make the commitments required to achieve at the expected level if there is constantly a risk of us having to leave at short notice.

- ❖ Suggestion: Respite services are crucial and should be accorded due focus and resourcing. A strategy for developing a professional carer workforce is necessary. Carers are not well remunerated for their work and should receive training and benefits befitting the responsibilities they perform each day.

We have a disability parking permit, which is extremely useful given the nature of our son's disability. However, there are sometimes insufficient places allocated at key locations, eg, the school and medical facilities. More frustrating is that people without permits seem to think that it is acceptable to park in marked spaces. These need to be better monitored and enforced. People seem that think that it's OK "just for a short time". It's not.

- ❖ Suggestion: that people who park in disability parking places receive not only a fine, but supervised community service in a disability facility or event so that they can understand the daily struggles of those less fortunate.

The government programs are limited and in some cases, inflexible. We receive a limited fortnightly carer's allowance and annual lump sum to help offset the costs of caring for our son. This is welcome but barely scratches the surface of the real financial costs to a family of caring for a child with a disability. The costs to date include specialty mobility pram (\$2000), medical and associated expenses (eg, currently \$180 per visit to the pediatrician who does not recognize the Health Care Card) and respite care (\$5 - \$15 per hour, approx 10 hours per week). In the future, we will need to purchase a manual, then electric wheelchair, purchase (~\$60 000) and convert a wheelchair friendly car, hospital bed and respiratory equipment etc and incur significant medical expenses. However, the key costs have been loss of income and providing suitable accommodation. Together, my husband and I have already foregone over \$100 000 per year in income (before tax) to take jobs that allow us to better care for our sons' needs. And as mentioned above, we have thrown everything into building an accessible house for our son's future needs. Building costs are currently around \$2000 per square metre in our area, so if you consider the wider hallways, accessible bathroom and circulation spaces needed to give a teenage boy some independence in an electric wheelchair, the costs are astronomic.

This means we have less super for our future, reduced ability to pay for a significantly increased mortgage and less savings or income to be able to manage caring responsibilities as I inevitably will have to give up work altogether. We did receive a small grant for modifications to our previous house, but despite communications, have still not received notification as to whether we can redirect those monies to a significantly more expensive housing undertaking. This year, I will again spend time and energy seeking further grant monies.

- ❖ Suggestions: Reinforce the importance of flexible working practices to employers by means of recognition, awards etc: Consider some form of payment or concession to parents who are required to assume caring responsibilities for their disabled child. This may be an income tax concession or carer payment, calculated on working hours as a carer. Consider means to encourage greater availability of accessible housing eg. Rebates for new houses that comply with the relevant Australian Standard, or allow waiver of stamp duty for families that undertake to build to meet their child's special needs.

The not for profit sector has been of mixed value to us. The associations representing MD across Australia are fragmented and fraught with infighting that, despite the good intentions of many involved, results in MD receiving less attention and funding than other conditions. Governments must ensure that they listen to the voices of all those affected, not just be swayed by the vocal self interests of associations that purport to speak on behalf of a limited disenfranchised membership.

- ❖ Suggestion: ensure that government does not simply tick the "consult" box by means of consultation with associations. Make the extra calls and talk to those who live with the condition every day.

Other associations, such as Carers Association, have been very helpful, but struggle (admirably) to service a diverse range of needs with limited resources, red tape and restrictive grant conditions. Marymead coordinates a wonderful "companion" program that allows our son special outings with a carer whilst we spend valuable time with our other son. Siblings Australia provided me with information that was invaluable in better framing and managing the needs of my older son – I understand that their existence is fragile owing to lack of funding. A small amount to keep them operable may have significant mental health benefits for thousands whose lives are changed forever by their siblings' disability across Australia.

- ❖ Suggestion: Certain organizations offer highly valued services to the community, with limited resources but huge hearts and commitment. Ensure that these organizations are adequately resourced, trusted with some flexibility in delivery and recognize the efforts of key individuals involved. It would cost considerably more for the government to administer these services directly.

Ways of achieving early intervention

As noted above, the early intervention program that our son attended was very good. The teachers were experienced, the ratio good and individual learning programs were developed for each child's individual needs. Our son would have been overwhelmed by a mainstream environment – he now enjoys school, has a happy and confident approach to learning (most of the time anyway) and is keeping touch with his able peers, with all the social and learning benefits that that brings. Fortunately, the Chief Medical Officer in our state identified this need prior to diagnosis and we were enrolled in the next intake – in retrospect, we were the fortunate ones. Had we received the diagnosis and not known of the program, it may well have taken another year for our son to commence at a crucial time in his development.

The current Labor Government's support of this program is most welcome, but doesn't address so many broader issues facing the disability community.

How the new scheme could encourage the full participation by people with disability and their carers in the community and work

My Son

Boys with DMD have a life expectancy of 18 years, so workplace participation is unlikely to be an issue for my son. However, boys can survive longer and certainly need the opportunity to be involved in the workplace or further study during this time to give them a sense of self worth, as well as contribute to productivity in some small way. In the advanced stages, DMD affects all movement and respiratory strength, so roles with minimal impact would be most suitable. I sometimes think that my son would do well in radio – he has a strong low voice and a lot to say. But more soberly, desk based roles that can be facilitated through the use of technology are likely to be most suitable. We are encouraging early learning of technology skills in the hope that this will allow our son to more fully be engaged in education, social interaction and possibly, the workforce. Given the likely intervention of illness, employers might be encouraged to allow flexible or casual work, either from home, or if transport and accessibility are available, from the office.

In our experience to date, community involvement depends on a wide range of factors –

- Availability of suitable activities in accessible premises eg. Wheelchair sports, scouts;
- Willingness of community groups to adjust for people with a disability and plan for their additional requirements eg. We know of DMD boys whose scout group simply built sedan chairs to allow them to go on bushwalks.
- Availability of suitable transport to and from activities;
- Availability of suitable carers/parents;
- Cost of facilitating access eg. Accessible buildings, transport, technology;
- Positive "can do" attitude by all involved, without prejudice, fear or naysayers. If this could be overcome, then involvement would be enabled significantly. As a family, we don't want pity, we just need practical help !

Carers

My participation in the workforce is essential to my financial, social and mental wellbeing. We have a massive mortgage, owing to the need to build suitable accommodation for my son. I cannot work full time, but am very fortunate to be able to use my professional qualifications in an interesting organization on a part time basis. The salary is necessary, but the social interaction with colleagues and clients is also just as important in maintaining my confidence, a sense of engagement with community and giving me valuable respite from my caring responsibilities.

With work and caring responsibilities, I don't have time for personal care and keeping in contact with friends in a meaningful way is difficult, so work is my connection to the "outside world".

I fully intend to continue working for as long as my son's health allows it. As noted above, having a flexible family friendly employer is a godsend. Provided that the work is done at the end of the week, I can take my son to medical and allied health appointments and juggle school pick ups on some days. However, I could not do this if it weren't for both paid respite care and the assistance of my parents.

My son cannot attend normal after school activities given his physical limitations and need for greater care and supervision. We have a respite carer after school who tailors activities to his strengths and interests. If she is ill or needs time to undertake further studies, I also have to take a day off. With a boy of 5, we can't have a new person each week, so we highly value the relationship that we have with her.

- ❖ Suggestion: recognize the importance of respite care through appropriate training, salaries and career paths. Little things like offering all family carers and paid carers free flu shots would help reduce the spread of illness and days lost to ill health.

Who Gets the Power ?

How to give people with disabilities or their carers more power to make their own decisions ?

My son will not be in a position to independently make significant decisions for some time, if ever. However, we will, as all parents do, listen and attempt to incorporate his opinion in our decision making. However, we would certainly appreciate having greater flexibility to make our own decisions.

As his parents, we are uniquely qualified to know our son, his condition and what is most likely to improve his quality of life, and our own ability to care for him. There is a cast of many involved in his care, ranging from medical, to educational and community services. We are the only ones who have the "full picture" and know his needs on a daily basis. In business and government, knowledge is power and the best decisions are usually made by those with the relevant information. In a family context, key decisions are usually made by the parents. It should be no different where we are the parents of a special needs child.

Decisions in my son's life are currently made by many, influenced by their various fiscal, temporal and professional interests. This can lead to a fragmented approach, although we are the kind of parents that strongly advocate in our son's best interests to achieve positive and workable outcomes.

- ❖ Suggestion: ensure that parents of special needs children are acknowledged as experts on their own child and treat them with due respect.

Other "decisions" are dictated by strict administrative timeframes and criteria. We were successful in receiving a small grant for certain modifications, but the time in which that had to be completed and specifications were difficult to squeeze into.

- ❖ Suggestion: consider the establishment of trusts in which grants or private funds/ contributions can be held, tax free, for expenditure on a broader range of equipment, treatment and services etc that may be needed. Most families would be happy to provide reasonable evidence of compliant expenditure and would be grateful for the ability to manage their own limited funds on requirements at the time that best suits their child's needs.

How to improve service delivery – including coordination, costs, timeliness and innovation

As a carer, we can only observe that the services available to us are fragmented, vary enormously in effectiveness and flexibility and are not coordinated across different providers. In practice, I coordinate the services that we receive from local and Federal government, 2 associations, 2 not for profit organizations, school and departmental level educational providers, GP, pediatrician, specialist neuromuscular clinic, local and interstate physiotherapists and OTs. I ensure that I receive a copy of everything and spend many hours providing information to others that may be helpful in my son's care.

It would be wonderful to have a reliable, trusted and experienced "coordinator", who knew our son, his condition, resources in our local area and our needs as a family – and could assist us in procuring what we needed and help us plan ahead. This would save me hours of work each week, much stress and allow me to focus on caring for my son and family.

Those that are, in my view, effective, are defined by one common factor. They are good communicators that take the time to listen to us as clients, are responsive and thoughtful in their communications. Those that are ineffective are defined by several factors: lack of funding, lack of staff commitment and unduly restrictive criterion or timeframe "boxes" to tick.

I am not sure what the answer is. However, it would seem that the following factors could assist –

- ❖ Parents/carers already play a key role in coordinating and managing their children's needs. Perhaps this could be formalized, recognized as a role worthy of remuneration, thereby giving carers a sense of purpose, worth and some income, whilst also giving them some greater responsibilities in terms of reporting and accountability;
- ❖ Implement training, recruitment, remuneration and retention strategies to attract appropriately qualified people to service delivery roles. They require all the skills and respect that a small business person does, often more given that the lives of many may depend on them. There are many older people who may have excellent skills, the necessary life experience, empathy and communications skills that may be suited to these roles.
- ❖ Innovation can only happen where there is a clearly articulated or understood requirement, time and resources to develop new ideas and the confidence and trust to implement them. At present, service providers appear to be working on the smell of an oily rag and there can be an element of arrogance amongst some service providers who think that they know better than those carers, who are "in the trenches". Therefore, you must make the time to listen, think, create and test. When busy and under-resourced, the "same old" is often easier.

Funding

Factors that affect how much support people get and who decides this

As the Commission's paper suggests, the level of unmet needs in Australia is vast and likely underestimated. Whilst it would be wonderful to have "platinum" care, such as that for Danish boys with DMD, we cannot necessarily expect that in Australia. However, it is terrifying to see parents and siblings of children with disabilities lose not only their child, but their dignity, their health and wellbeing, their jobs, their financial stability etc. It is unconscionable to use parents as unpaid, unseen and unrecognised labour. The cost to those families, their communities and the economy is huge.

- ❖ Assistance with respite services (availability, quality, reliability and affordability) would help parents retain their jobs, their dignity and mental health.

Each family's needs will differ depending on their circumstances, primarily the condition of the person with a disability. Given the high level needs of DMD boys, including throughout the night, it is common for both parents to have to give up paid work to provide care around the clock. How can they then pay their mortgage and the many medical expenses they face? How can they contribute a little to super to provide for their future, once their son has died?

There is not "one number" that can be put on how much support people need. There are ongoing expenses, one off expenses, expenses that cannot be anticipated and huge lost earning and saving capacity. A diagnosis of disability is often a one way ticket to poverty.

We appreciate the little "breaks" that we get along the way eg. Health Card, Companion Card, Mobility Parking Permit, Carers Allowance etc. However, a few hundred here and there throughout the year does not cover the loss of income that we've already sustained and the further income that I will lose as my caring responsibilities increase. The banks will profit, as our mortgage extends over many more years. The government will lose my income tax and I'll become more reliant on social security in the future.

It is difficult for carers to see proposals for parental leave at \$570 per week to look after a healthy child, massive worker's compensation payouts for injuries that are fortuitously sustained in the workplace rather than by genetic error and even massive \$37M claims for alleged discrimination in the workplace, where there may be limited future needs, but not anywhere near the scale of a terminally ill child. Whilst these measures may not be realistic, or even sought by those with disabilities and their carers, please consider the glaring

inequities in considering what may be appropriate for hard working families that work around the clock in conditions that would likely constitute breaches of all manner of work safety, discrimination and bullying laws if they occurred in a workplace.

What would really help is a few well timed and targeted breaks along the way. For example, we have just sold up our house (incurring a loss in a falling market, since timing was not a luxury that we could afford) to build more appropriate accommodation for our son's future needs. Whilst there is meager assistance for home modifications, there is no assistance available for this sort of venture. As suggested above, perhaps the government could consider some tax relief, eg. waiving stamp duty or land tax. Along the same lines, perhaps those who forego full time positions to undertake caring duties could be granted some form of income tax relief on their (part time) income, or their partner's remaining income.

As to who decides the amount of funding required, it should not be a question of how do we divide the small bucket available. We need to agree, as a society, that children with disabilities should be supported to achieve an acceptable quality of life and that their carers (often family), should not be treated as slave labour. Disability is a risk that everyone faces, so a broad based tax should be used to fund it.

How to ensure good aspects of the current approaches are preserved

Listen carefully to those with disabilities and their carers, and the various service providers. There are many good people in this community with big hearts. It's often undue red tape, regulatory requirements, shoe string resources and poor communication that bring otherwise good services undone.

Reducing unfairness so that people with similar levels of need get similar support

Conditions such as DMD have a predictable course. A sample of those whose lives are now lost will give you reliable information on support requirements. Individuals and families will vary, but a flexible lifetime support package could be worked out without undue difficulty.

DMD also has a steady rate of incidence – 1:3000 male births, so it is also relatively easy to work out future costs. However, given medical advances, DMD boys can now live 5 – 10 years longer, at an advanced stage of the condition, requiring 24/7 care, so these increases need to be worked into DMD future costing, and other similar conditions.

As a family, we would support a scheme that provided some future funding certainty. This would allow us to better plan care for our son and the arrangements of those involved in his care.

Organising and Implementing a new disability policy

As to how to finance such a scheme, my view is that disability is a risk inherent in being human. Therefore, we should, as a society "insure" against it. All people are at risk, whether born with a disability, disability is acquired or they find themselves caring for those most severely affected. Therefore, taxpayers should be required to contribute to the scheme, thereby recognizing the risk and spreading the burden.

Many families would also be grateful for a more flexible disability trust structure. Under the present scheme, we cannot invest money for our son's future needs. His needs will be intense over the next 10 – 12 years and then we will lose him. However, the trusts can only be used for needs once an adult cannot be cared for by aged parents.

The need for a new disability scheme is urgent. Before my son was diagnosed, I gave to charities as a decent thing to do, but was blissfully ignorant of the pain and difficulties involved. Now, I am really scared for the future of my son and family. Care needs to be taken to get this right. It affects the lives of so many.

However, much can be done immediately -

- reduce the red tape and duplication;
- recognize a single assessment, particularly where conditions have a predictable course and cannot be treated;

- recognize the expertise and contribution that carers make to our society. Our society applauds the work of our Army Reserves, our fire fighters etc. When lost or returning, they are heroes. There are carers performing heroic acts all over the country without respite, assistance, thanks or respect;
- providing reliable, cost effective, respite care is the single most valuable contribution that the government could make for our family. With respite, we can continue to work and to some extent, make our own way. We can also remain engaged in society, so important for our mental and social health and consequently, our ability to care for our son.

End