

TOWARDS A REAL NDIS AND AN END OF EMPIRES

A submission to the NDIS Bill 2012

Introduction

The Every Australian Counts lobby have asked their mailing list to make submissions in support of the NDIS. They accept that the proposed NDIS equates to additional disability funding which they view as “a solution” to universal unmet need regardless of who it targets or how it is administered. They do not mention that it bears no resemblance to the sustainable, immutable, national and equitable solution all PWD aspired to, or that it is a misnomer for a genuine insurance scheme. The level of denial on both sides is a reflection of the contempt of society for persons with disabilities, (so ingrained that the disabled themselves internalize it) and the contempt for the Australian public in general – that a process, a scheme, can be made law, for which none of the descriptors are truthful. If nothing else, please change the name of the scheme to reflect the actual disability policy outcome. The first section should define the terms themselves and be truthful definitions. Isn't this the basis of any policy/law?

My personal submission aims to point out that whilst the construction of this mooted NDIS appears to address unmet need, it is very much a solution that is a product of the industry itself – and does not put the interests of people with disabilities paramount. The planned “roll-out” of the NDIS over the next 5 years, I have no doubt, in time, will come to be regarded with as much sadness, disappointment and incredulity as we now regard the “then altruistic” removal of biracial children from their aboriginal parents last century. This NDIS “reform” is actually inhumane, inequitable in its design, as well as being unsustainable.

Just like the Creation Museum near Cincinnati USA, the NDIS architects have started with their industry focused vision (which is not substantially different from the inefficient and unfair systems we currently endure) and worked backwards to justify it, ignoring the widespread locations of unmet need, coldly dismissive of persons with little to no support at all for years to come, in order to picture the future as they see it - not as we need it to be. Where are the educated and experienced PWD who have the authentic lived experiences and truly seek change in the design of NDIS? For that matter where are the intelligent, educated victims of child sexual abuse amongst the commissioners selected for that social problem? Whilst our government do not employ and consult those with the deep knowledge of each problem, there is a whole authentic perspective that society can never hope to understand and to address. The disability industry in its often misplaced altruism is designing a system convenient to them firstly, and that includes government departments. This is the only obvious conclusion if so many individual disasters will be happily left ignored for the next 5 years.

The unmet need for PWD in this country varies from state to state and within states to the point that there is no logic to winning the lottery for help. The productivity commission established that. But we have thousands of disasters, which combined equate to a Tsunami of unmet need. The downstream affect of these thousands of disasters is suffering for the PWD and fractured dysfunctional families. These disasters combined create a huge personal and social cost for the health sector, disability sector, mental health and productivity of our country. It is only fitting that our government decided to address this longitudinal disaster for thousands of persons who have never had any care packages and few services. But it has been developed without consultation with any of these end users it seems, because incredibly, there will be likely be no help for many of these “poster” PWD, whose pathetic lives so incited our politicians to condone a huge hike in services and payments for the next 5 years. Our neglect which has provided the stimulus will go ignored and using geographic criteria, and ageism (in two locations as there is a further caveat

that recipients must be very young children or under 24yrs) a scheme will necessarily be trialled with many PWD who already receive some support or adequate support.

Imagine there was a huge natural disaster in a third world country and Australia committed billions to alleviate the suffering of those people. Would there be any humanity or any logic in allocating that aid to people in a neighbouring district, who have some services and some quality of life already and subsequently ignoring those who are actually in need – unsafe and desperate people? Of course not, it would be inhumane. I do not begrudge the standard of living of PWD by luck, effort, guile or any means but if NDIS is truly meant to rescue those most in need, why is it designed to do otherwise by geographic criteria and by as I have heard, by in some cases supporting those already receiving good support, even more. Indeed, I would like to know the % of the new disability funding (I am loathe to perpetrate the false believe that it is an NDIS) will be used for the disability industry itself - workers and infrastructure.

If you cannot understand this mistaken priority and the boon for the disability industry in the main, then you have not understood the experience of a person with a disability trying to be helped in Australia. If so, you must believe the dismissive generalizations about the “grey army” in the National Disability Strategy document. The NDIS cheer squad would have us all believe that we are equally in need and “united we stand”. But to understand marginalization and neglect, it is largely a question of gross inequity, and in my experience the bias against those who struggle to help themselves and rail against wastage whilst the person they care for is held in contempt; every bit as much as a real NDIS is about insufficient funds. And, if the mere budgetary allocation of funds is going to be the funding source, it is ever more important to ensure that those who need help most receive it based on their severity and their personal lack of material ability to obtain support. For without a sustainable tax/levy, this round of disability funding will be exhausted before those who have managed to survive until 2018, are allowed to apply. We will receive the same answers we do now from our DS, “the govt is broke, there is no more funding...”

The Grey Army and The National Disability Strategy

The National Disability Strategy, once again written by the disability industry including political leaders and not a consensus of persons with severe disability, confesses almost as an apology that there is a “grey army” whose unmet needs are somehow secondary or inferior to those favoured or handpicked disabled citizens selected for individual funding or block funded accommodation opportunities etc. According to the National Disability Strategy, these PWD did not apparently meet the strict criteria of overstretched state disability services - but in reality at least in Queensland, the system is for the most part arbitrary and random.

This assumption is as bad as Lance Armstrong being unable to accept that he is a cheat. It is a denial of the mistakes made in the past. The system and the disability industry has failed us in the past as a whole – not that there haven’t been valiant peak bodies and a great number of valiant persons providing real and helpful services. The problem has been with the management of both government and non-govt disability services and what motivates these persons making decisions at these levels ... in my experience – lack of vision, lack of empathy, sour investments and costly assets, exorbitant salaries and benefits, lack of deep specialized knowledge for the disorders they service etc. umbrella organizations attempting to be across dozens of disorders; and of course I admit, the severe shortage of funding – but this last monetary fact is not entirely to blame. I have known organizations that are run so badly that only a few cents in every dollar raised finds its way to the end users they service.

As self-appointed cheerleaders of a very poor facsimile of an NDIS, the majority of stakeholders miss the whole point - the depth of unmet need. There is no “grey army” who didn’t meet strict and fair criteria. Why is there no recrimination for the arbitrary support that has been given in the past or failure to demand value for money so that so very few could be helped? Two families in exactly the same material and familial circumstances with a severely disabled dependent of

same age and ability can be at opposite poles in terms of support – one with grandiose support, 24/7 care, choice of housing infrastructure and companions and the other with no funding whatsoever or merely a few hours flexi support, which is only partly funded. Yet the latter cases are so easily dismissed as “the grey army” who never made the cut for the next 5 years? Why? Because the disability industry is going to put everyone's name in a barrel and pull a few names out again. Need and struggle and adversity mean nothing because of what they have designed.

Of course I am speaking from experience, I have only my experience as a reference point – my other experiences like those of the NDIS architects are at best second-hand. But I do have an authentic experience of being discriminated against as in the scenario I describe above and I know many in my sphere who fall into either group. Anyone who knows our disorder knows it is a very degenerative disorder with almost universal progression. So at the same ages, almost all cases are equally incapacitated in the same ways. I can only extrapolate from that and from those who have shared their experiences with me in my network, that there are many in the dismissed “grey army” who have never been prioritized because somehow they don't deserve to be, yet they have the same pressing needs for assistance, the same tired, aging primary carer struggling to care for them, as those who have for some unknown reason received the compassion and the level of support that allows PWD to be less of a burden or live independently from aging parents.

I saw the stories of some NDIS advocates featured. One or two were beside themselves for want of services whose child received more services in one day than my son did in a week. I couldn't understand how they could be so ungrateful by comparison - but they weren't they were broken and tired and attracted so much sympathy. I thought, surely my son and the children of aging carers with comparatively little support will be helped by comparison. But I was wrong - it is still a question of someone's "perception" of someone else's suffering, or is it that we simply can empathize with people of our own class and nobody else? How can I not feel that it is a question of distribution that some are allowed to cope while others flounder. I am exhausted from the drudgery of 20-30 yrs. of care and I can't be the only one, how many struggling carers are in the 60's, 70's and beyond? How many adult PWD have never felt they have reached their potential? If my physical and mental health and relationships are suffering, I can't imagine the stress on the elderly carers.

How would you feel when you are brushed aside, whilst many who contribute less to society, those who are less disabled, those who already receive an abundance of support are going to be handed a revolutionary new method of receiving their existing support in addition to further support. These are important questions. One can accept the gutting news of ongoing neglect if help is prioritized fairly; but not if it means only a few continue to be supported based on continuing arbitrary criteria – and in the case of the “trial sites”, it is a geographic criteria. In the case of early intervention, the physical logistics mean that children are manipulated with far more ease than trying to bathe, toilet, dress, transfer, assist a person who might weigh more than you do - and for decades!

Added to this contempt and promise of ongoing neglect, our experiences tell us that like every other disability handout in the past, at the 2018 juncture, it is highly likely that there may be no more funding left when one finally does make it to the ‘top’ of the arbitrary cue. Why? Because there is in fact no insurance scheme planned – only handouts out of budget. Idealists envisage more handouts coming on line but my son and I have for 20 yrs been given these excuses “that was then, the funding has run out now”, “it is hard to get carers in rural cities”, “we have so many clients we can only give each of them 3 hours flexi”, “they are old deals”, “your son is as high on the list as he can go”, “there is no more funding” “the government is broke” etc.

These kinds of statements represent the level of empathy a young adult man is likely to receive if he has a severe, physical and chronic condition - even if he has lived beyond his predicted lifespan of early 20's. Increasingly unknowledgeable managers are trying to make decisions when they have little detailed knowledge of particular disabilities, the services their staff attempt to provide and only biased experiences of any or one type of disability. Obviously there will be

some persons with disabilities in the “grey army” who require only a little support and who are denied that assistance because they are ranked lower because of their function and success. I am not saying they do not deserve assistance – of course they do – we all should strive for self-actualization and a real NDIS should be able to provide that for all citizens. But the arbitrary nature of historic selection and promised selection means that there are severely disabled persons without support in the grey army, who have never been granted a package of care, or denied independent accommodation in vacant facilities; and whose families struggle to pay for a few hours flexi-care if they can be granted the allocation of hours by overstressed local service providers. Otherwise they bear the weight of tremendous adversity ungrudgingly or grudgingly (itself another problem) every bit as much as their peers whose children have won 24/7 care and purpose-build facilities.

We parents who either give up our careers to provide care, or who work all day and then all night to provide both survival and care (neglecting their PWD in the process) have little quality of life filled with drudgery and hardship. We are regarded as “uneducated” or unmotivated. We haven't ingratiated ourselves to the right people who might help us. We lack the skills to lobby for our own children. Young carers, whose child has not yet degenerated, who have not yet given up their careers or juggled physical care and a the tatters of a career, cannot understand why we have had so little success. Perhaps getting nowhere is too overwhelming and paradoxical, perhaps as I have, one has been working hard first to help support my family materially, and secondly in a voluntary capacity to ensure a better medical future and prognosis for all with the same common lethal disorder, at the same time as living with anticipatory grief for 20 years? I don't regard myself as stupid, I somehow thought that in a welfare society, physical assistance as I aged would be fair and I would not have to fight bitterly for equitable support for one of my children either – it is hard enough working towards medical and research equity. My platform has always been our disability group and perhaps that is why my son's needs have suffered? Is it any wonder that I am so bitter, that my son continues to be sidelined almost in direct opposition to our striving for the social good?

It is always implied when you try to ask either case managers, service providers or successful PWD living with good support, independence and dignity: “You didn't work as hard as me. It was a lot of work. I am skilled at personal advocacy and you are not. It is your fault that you lack skills. You have to be in the right place at the right time.” “You have to do your homework”. Some general disability organizations advising identical PWD claim credit for advocacy but cannot provide you with the same service. You are left to work it out for yourself with few tips and platitudes about all the people they have helped – it is not a science even to them - simply a lottery. Perhaps it is the difference between urban and rural families – certainly there is a great disparity between states but also within states. The latest advice I have received by a casual observer in order to obtain lifestyle support when being assessed or interviewed, is that both the PWD and the carers need to break down and sob to communicate their pitiful existence well enough to elicit some compassion. “Then they can't do enough for you”.

As we are penalized for working for a living (unable to gamble on social support) and caring (doing both jobs badly despite mental and physical exhaustion) so we are penalized for our stoicism, penalized for not reaching our absolute breaking point. But I assure the Senators that one can live for many years on the verge of that breaking point and rally from short voyages beyond it with great frequency.

When faced with such inequity, we are given lots of excuses: more disabled, less disabled, more than one child with a disability, single parent, unemployed etc. Indeed these are some mitigating factors, but some with grandiose support have exactly my family dynamic. Apart from the irony that a working parent caring for someone with a severe disability actually has twice the burden as someone who doesn't; because we feel they must to guarantee survival, some quality of life, the power to purchase transport, wheelchair friendly housing, medical equipment and sometimes life-saving equipment. To do so we must neglect in many ways the very person for whom they care.

What do the NDIS architects prioritize then? Making it even more inequitable for 5 long years...sending the disaster relief to arbitrary persons in arbitrary locations (sites), families with such young children that physical exhaustion and damage is not yet a problem... so that the industry can “work out a system” of paying it and funding it and servicing it. This very idea focuses on the jobs and the industry – it’s all about them. With this inhumane logic PWD are still somebody’s commodity, somebody’s meal ticket. Our daily disasters MUST languish unless NDIS planning prioritizes those with unmet need – after all isn't humanitarian support the whole point. Go back to the drawing board and call for stakeholders from disease specific organizations and PWD themselves restore some equity to everyone's level of support who is in similar circumstances.

My Story

In answer to the EAC question, Why doesn't the disability system work for your family: It doesn't work because it is discriminatory. Disability Services have no criteria and we have been sidelined historically and made to feel worthless compared to PWD who may be less disabled or so disabled they are incapable of contributing anything at all to society. At 25, my son is paralysed by Duchenne muscular dystrophy. He has (without the support enjoyed by his many of his peers in other geographic areas) completed a university degree unaided for the most part. He often lacked hygiene, mobility, he often dodged fallen trees and once a snake to drive his wheelchair from home to uni nearly every day for 5 years. He volunteers weekly to help persons with a different disability. He actively participates in the local community and the community art scene as a committee member and performer and he volunteers for his disease charity. He has served 3 yrs on a regional disability council - itself a farce since he was forbidden to encourage anyone in the community to contact him with concerns – yet another example of how we “must be seen” to be supporting PWD only, not actually doing it. Yet PWD who pursue their own gratification solely whether they have the ability or not, who are less disabled, or who have more function, or conversely who are not even aware of their surroundings, those who are younger or they may be a lot older, those who have not contributed in any way to mainstream or the disabled community, who have a slight mental disability that is not at all life-limiting or life-altering, can access opportunities to live independently. The only opportunity my son has been offered was untenable and unsafe with no night shift and a subsequent offer was in a distant country town away from family, friends, volunteer obligations and the art scene in which he is involved. We were not even allowed to source different services to check up on him in the night in this well-appointed facility next door to both his volunteering obligations and the local theatres. When we tried to explain that his care for medical reasons is largely at night being semi-independent in the daytime, so he could receive care equal to some of his peers in the cities or interstate, this was dismissed by the government with insensitive platitudes about how we rejected two offers of independent living. If the alternative was death, was that a sincere offer?

The industry

Organizations in both domains can spend disproportionate amounts on infrastructure. Just a few cents in every dollar can reach PWD. Orders for a wheelchairs and pressure relieving mattresses and chair cushions can be lost for up to a year as one waits in such discomfort. All powerful social workers decide who is most pitiable and decline to offer to help those in exactly the same circumstances. There is no criteria beyond the arbitrary judgements. There are no level playing fields for one to apply and be considered equitably. To be fair, there are individuals and organizations who make a good attempt but these are usually recognized centres of excellence internationally and unrecognized and floundering at a national or state level. But as soon as those with a deep knowledge and integrity resign or retire, even those institutions become three ring circuses. I suspect that there is more unacknowledged expertise in the treatment sector being lost in this country than we are creating.

22 million dollars in extra respite funding was made available to those under 25yrs over the next handful of years in Qld. As my son only just qualifies until late February, last year I asked how

one might apply. I was handed a glossy DL brochure about this singular initiative at a employment expo for youth with disabilities. The transition officer placed it in my hand as if she was giving me a great gift and a great opportunity. But when I inquired about how one might apply - the answer? Of course you can not. This support will be given once again behind the scenes arbitrarily to whomever the disability industry wishes. Can we expect to be noticed and rewarded when nobody knows we exist? Case managers are only assigned to a person when a person has a pending offer for accommodation and as I have explained that doesn't happen very often. Once again a lot of money, a glossy brochure, shrouded in mystery unless you somehow can pluck the right heart string, even if you knew where that was to be found. BTW the brochure was on the government display table 5 feet long and manned that day by no less than 8 government employees (my son counted them apparently). This is the same department that tells him "there is simply no more money" "but those people have high medical needs" (forget about the fact that my son is already on borrowed time and on a ventilator. If they don't want to see you - they don't.

Unless we overhaul the priorities and the basic philosophy and mission of the disability industry, in 5 years' time, can we expect to be handed a glossy brochure with the meaningless promise of "NDIS" on it? What a good start we are off to already when most of the referents in the acronym of this scheme have not been defined logically or honestly. How would you define "insurance"? Only as "funding", "handout", "budget allocation"? Why are we encouraged by our own sub-culture to turn a blind eye to this farcical nomenclature?

The EAC campaign asks potential advocates what three features of the NDIS will have the biggest community impact, and their extensive list of diverse services for one to tick off demonstrates the trivial context of their own concept of unmet need. My answer - simply equity and fairness in providing real physical support - the individual can choose his own solutions based on the support required. If we are going to have our wheelchair's faster and with more personalized service from one SP, the other SP's will soon have to improve their knowledge and service to be competitive. The free market will keep everyone striving for best practice. There is no need to recruit thousands of planners and people with local knowledge to refer us to services...none of whom have any direct lived experience of disability.

When one's needs are met one can be happy, but if as tax payers, (in fact it is the tax payers who are working and caring for a PWD who are penalized ironically) our assistance is not comparable to persons with the same life-limiting and disabling limitations, then this contempt and disregard makes us less likely to cope with our ongoing adversity. Why should the government spend more money on veterinary bills for an assistance dog for an able bodied youth with a mood disorder, than my son who is virtually paralysed? How can families like mine live year in year out with such contempt and continue to work, care, and in our case volunteer hundreds of hours every year to advocate for all Australians affected by tan male "invisible" disorder of 1 in every 3,500 males...so we can all have access to up-to-date information and first-world medical care?

Not National and Not Fair

"Of all tyrannies, a tyranny sincerely exercised for the good of its victims may be the most oppressive. It would be better to live under robber barons than under omnipotent moral busybodies. The robber baron's cruelty may sometimes sleep, his cupidity may at some point be satiated; but those who torment us for our own good will torment us without end for they do so with the approval of their own conscience." C. S. Lewis English essayist & juvenile novelist (1898 - 1963)

I made my submission to the productivity commission because the disability system sidelines my adult disabled son historically despite severe disability. All PWD in Australia banded together to give a complete picture of our adversity and we trusted that as with any disaster, those worse off would be helped first. I am incredibly disappointed that the manifestation of the NDIS ignores those in need of respite or wishing to live independently... more so those with older worn out

carers. I am disappointed that the "NDIS" will be trialled according to geography, politicking and the arbitrary needs of the disability industry, panic stricken about reform and in complete denial about past inadequacies.

What compliance is happening? My son has never been contacted by the government to verify that he is in fact receiving flexi-respite however irregularly. Surely checking with the end user once in a while would ensure honesty of operations. The degree of his comparative neglect has left me to wonder whether someone else isn't being serviced in his place. Locally, I have drawn attention to severely disabled persons unable to move or call out being left unattended between 10pm & 6am, because this 'fact' if I was not misled, made my son unsuitable for a once-in-a-lifetime opportunity, after months of being "groomed and interviewed" for this community living accommodation. I write community living loosely because in fact it seems an institution in the middle of a community where inmates have no ability to interact, even to the point of being unaware that they are abandoned all night because I was told the person paid to sleep there all night was not paid to wake up. No feedback has ever been sent to me, yet any other govt dept. would have made this the subject of a ministerial inquiry! A national structure must demand and monitor standards – our government must investigate discriminatory or unsafe reports. Our disability industry needs total reform in addition to funding that is not finite & liable to run out. Financial & managerial visions of a wonderful "self-managed" system are such a small part.

Misleading nomenclature

The current actualization of NDIS is a meaningless acronym. At its core it is semantically flawed. NDIS is bandied about without regard for this intrinsic meaninglessness, holding PWD in contempt of the obvious lie of its reality. At most NDIS represents more disability handouts (albeit self-managed) out of budget to the same few PWD and perhaps in time, to a few more PWD. It is not insurance, there is no levy, and no nurturing of collective responsibility via a levy despite claims that it is a form of "social insurance". There is nothing national about it for reasons we all know - we are not stupid. There is nothing immutable or sustainable about the current official manifestation of NDIS in Australia. Funding made available on a whim from budget, and competing against shifting priorities will never be sustainable - already it is not enough.

PWD are largely disenfranchised from the implementation of what was a promising and authentic solution to their adversity, drudgery and unmet need by the misplaced altruism of those highly paid for our sakes. Give experts living with each disorder the mandate to assess persons without any funding whatsoever and ensure a funding stream and you will be making a good start. In addition those employed in supported employment will not themselves require assessment – a saving!

Penny Wong's definition of NDIS on Q & A is perhaps rooted in basic illiteracy or a really great "snow job" more likely being a very intelligent person. For Ms Wong, it's all about "ensuring that PWD" There you have it, our government mistakes "ensure" for "insure" - perhaps that's why we don't have a real NDIS? The word ensure is a verb, something you agree to do (however well). And depending upon the surrounding terms of reference, not necessarily a bad aim. But "insure" means to indemnify, to underwrite. It is much more official and involves a legal obligation to meet one's needs should something happen e.g. pay for damages to a car in an accident, pay for the rehabilitation of a person in an accident. Although my first family cared for 50 yrs for a brother with all three limitations of severe cerebral palsy, my interests lie with 1 in every 3,500 males randomly selected to have a genetic mistake in one's Dystrophin gene; to live with comfort and dignity. You have to wonder if the generalized guarantee is as good as the official one, the one proffered as the only real solution by the productivity commission and all those who informed that report, when no levy is in place to pay the premium which would guarantee sustainability. Interestingly in a lightning fast vote held on Q & A, a sizeable section of the audience indicated that they would pay a tax to fund a real NDIS. But being an election year, no political party has the guts to do the right thing.

Conclusion

Thank you for reading my submission. No doubt the disability industry, the altruists, the cheer leaders and certainly all NDIS stakeholders will be horrified in my insular, selfish, "sour grapes" tirade herein. Interesting that those with "adequate support" or with "survivors syndrome", those with friends in high places being the only thing to distinguish them from me, or those with the skills to emotionally "break down" enough to be helped and their lives actualized by government packages of care or block funded opportunities, (and perhaps some who are simply lucky) will be the first to condemn me being for being so negative, for not standing together, shoulder to shoulder united in our disabilities so that the lucky few can receive more out- of- budget handouts.

Over the next 5 years of "getting it right" with simply more funding out of budget, thousands of elderly carers will be enduring worse than the drudgery and shooting pains I feel in my arm daily coupled with an inability to remember a night without waking innumerable times from caring for an adult PWD. Thousands of adult children, despite either ungrudging or grudging care given to them, will continue to suffer by choice and demand as little as possible of their carer, because to demand one more thing in that hour or day would be ungrateful, cruel and perhaps even the straw that breaks that carer fully.

The PM's gravity in introducing the NDIS Bill was very moving. As a person affected by familial disability for 2 generations, I was moved. I have no doubt that the PM sincerely feels expansive because she understands that the eventual repercussions of more disability funding, will alleviate a great deal of suffering long term. But there's one thing I can't understand and I have to wonder whether anyone who has no experience of being severely disabled or in dealing with our current disability systems can fully "know" or understand. I risk being asked again, "Would you be so critical if you lived in a trial site" which is what I have been asked at least once to silence me in an online forum. Always there is a risk of being accused of being told you are personally disgruntled and self-interested and ironically those who have adequate support are of course not and never were "self-interested". But it goes deeper than that, if you have been sidelined for a significant length of time, you extrapolate that to people in similar circumstances or the great many who must have worse circumstances.

If you have been denied assistance because of paradoxical reasons like geography or because of a lack of information, a lack of funding, because you were too disabled or not disabled enough blah blah, the current manifestation of NDIS semantically and realistically perpetuates a system that is discriminatory and subjective. NDIS espouses to be neither of those things but in fact it is. When the PM was elaborating in detail about the depth of despair of PWD, she painted a picture so very well, I could have wept. I saw that because my son has no personal funding, that I was looking down the barrel at another five years of drudgery, sleeplessness, pain, mental anguish and worsening relationships with my son, my family, my workplace and my community. My husband who is not our son's primary carer, left his job before retirement for two reasons – his own worsening heart condition (the second artificial valve is leaking) and to be able at least to keep an eye on my son whilst I am at work. This change in financial circumstances doesn't even warrant a reassessment of my son's circumstances, nor do my own medical problems.

But the very worst of this contemptuous phoney NDIS is the fact that my son in an effort to delay "breaking point" endured so much in silence every day throughout adolescence and beyond. He denied himself comfort, access, cleanliness, hunger, thirst, companionship and dignity regularly since becoming wheelchair dependent at 9 yrs. Today, he is an old man with nothing but white connective tissue under his skin, no muscle at all – imagine that horror? This is the unrecognized horror of Duchenne muscular dystrophy, the most severe life-threatening genetic disorder of childhood affecting 99.9% males and occurring in young men at three times the rate that breast cancer occurs in young women. He has no ability to move except for the slight movement made by the muscles left in his fingers. Imagine how uncomfortable he is night and day? But his government regards him as if he were an able bodied person with a normal life-span who is sitting down, because society is not interested in what is missing under his skin. Nor does my son necessarily want everyone to know his physical horror. He is housebound for the

most part but sometimes risks unsafe situations often alone without companions going out into the community to give his parents a few hours alone or simply to feel a part of the human race. You can't control that level of sacrifice. It is made by choice or rather by a lack of choices. I have no doubt that the majority of the general public who see his guts and determination and as a result, have helped him open the tap on this leg bag, replaced his fallen hand to the joy stick, switched over his ventilator battery, placed a drink on his tray, do understand the true nature of "social responsibility" and the importance of a true sustainable NDIS - not so those with no experience of severe disability who have designed it.

In addition to comprehending that level of stoicism, my son doesn't sit playing video games waiting to die – he engages in the community, volunteering and contributing – so it isn't as if he believes "the world owes him something". You can't imagine that level of humility and service, which weekly goes unrecognized because nobody bothers to compare him and those like him, to many PWD often less disabled, whose families can communicate their hardships well enough to be considered for independent living.

But I make no apology, there can be no successful NDIS implemented unless it involves those persons living with a disability who truly understand the degree of inequity, marginalization, and outright contempt of our government and our own industry sector. Because the community have always voluntarily been so kind to my son - I have no doubt that society at large do not regard him with contempt.

There is more at stake than the "altruistic feelings" of a politician or an administrator, or a few citizens disgruntled about a small levy because they fail to imagine a twist of fate could incapacitate them or their children or grandchildren at any point in time, or the fear of a political party wishing to stay in power or gain power – there are real lives and missed potentials and pain and suffering at stake for the foreseeable future. If you have truly attempted to understand my "sour grapes" for my son, that is the first step because dominos fall one at a time and when they do there is a ripple effect. This is the start of real change for all. If you have glimpsed my adversity & my son's neglect and unfulfilled potential, then I have done the only thing I know to do to help everyone in Australia with a disability to be helped in a timely fashion by a real NDIS – a strategy that 'walks the talk' in being national, fair, immutable and sustainable because not only will the acronym be honest, but by being focused on unmet need first, a tree of official support will grow that will sustain all Australians in the future with disabilities, to an acceptable standard.

If our government would be brave enough to put PWD ahead of their fears of losing elections, if they would implement the only sustainable method of funding adequate disability service through provision of a tax or levy – (please see my appended fictitious scenario of missed opportunity for contemplation), if they would ensure that those who have the least support were helped immediately in the interests of humanity (supposedly a characteristic of a civilized society), if the system were truly national and not dependent upon geographic location or age, if there were quality control to ensure comparable provision of services, then I could accept that my son is not worthy of the same level of assistance as those rated more urgently. I could be happy that those with greater needs could be serviced first, that their elderly carers would be spared pain and exhaustion and would gladly resign myself to the "grey army" who really do not meet a fair criteria. I assure you that I could continue to endure my hardships and my son's quiet sacrifice.

Thank you for this opportunity to share my experiences. I would welcome the opportunity to discuss them further and help to design a fair system of addressing unmet need.

To gain further understanding about how incensed I am that our one immutable, realistic, fair, national, socially responsible dream, which won over the productivity commission, has been bastardized for every end other than serving PWD with unmet need today, please visit my online commentary:

<http://www.scoop.it/t/towards-a-real-ndis-and-the-end-of-empires>

Deborah Robins

Appendix

Below, I have altered a real news report from Jan 27, 2011 -

(with Chris Zappone, BusinessDay, Daniel Hurst at the Brisbane Times, and **Bloomberg News**, Reuters, AAP **Read more:** <http://www.smh.com.au/business/levy-to-pay-for-56b-flood-bill-20110127-1a64x.html#ixzz2HNwFG8d0>)

I have deliberately replaced the word "flood" with "disability" using the automated "find and replace" utility of MS Word. I have deleted a few passages, which can only be used in the context of the "floods" or which exclude victims themselves from contributing to the levy.

I did not alter figures although our govt could easily calculate a fair rate.

Can you see how easy it would have been for our Prime Minister and our Government to address tens of thousands of daily disasters occurring in Australian homes year after year?

Can you imagine how equitable, immutable and sustainable a real NDIS might have been?

Levy to pay for \$5.6b disability bill

Date January 27, 2011

Gillard announces disability levy

Prime Minister Julia Gillard announces the disability levy that will be part of a \$5.6 billion dollar disability package.

Update Taxpayers earning over \$50,000 a year will be hit with a new levy to help pay the estimated \$5.6 billion bill for disability devastation across eastern Australia this summer.

Prime Minister Julia Gillard announced the 12-month levy would apply from July 1.

How the disability levy will affect you Green programs chopped

Those earning between \$50,000 and \$100,000 a year would pay an additional 0.5 per cent disability levy tax, while those earning over \$100,000 would pay an additional 1 per cent tax.



Prime Minister Julia Gillard ... the levy will be imposed for one year. *Photo: Penny Bradfield*

"In other words it is not like the Medicare levy, which for most taxpayers applies to all their income - it is like income tax rates which apply only above certain income levels," she said.

Ms Gillard said under the changes, those on a wage of \$60,000 would pay just \$1 a week more than they are presently paying since the levy kicks in only on the additional \$10,000 earned above the threshold. Those paying the top tier tax would pay an additional \$5 a week.

Queensland Premier Anna Bligh welcomed news the state would be receiving an upfront \$2 billion cash transfer from the federal government, saying it would help begin the rebuilding work.

"When it comes to the levy, I understand that nobody wants to pay more, but the people of Queensland didn't want this disaster either," she told reporters in Brisbane.

Ms Gillard told the National Press Club, "We are grieving, we are burying the dead."

But she said disability devastated areas are now "moving from crisis to recovery".

She said deferring the cost for future years was a "soft option, and I am not prepared to do it".

She said the federal government would make an immediate \$2 billion payment to help Queensland's disability-affected communities.

Legislation for the tax will be brought in as soon as Parliament resumes the week after next.