# Submission to the Productivity Commission Inquiry into a new long-term disability care and support system for Australia

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Fighting Chance is a registered charity to help people with disabilities and their families which I established late last year following my return to Australia from disability exile in the UK, a return forced upon me in 2008 as a result of the death in the UK of my husband David from cancer. I decided to establish Fighting Chance, in David's memory, for several reasons.

One was that it seemed a fitting way to honour David's tireless devotion to our third child, Shane, who is very severely disabled with cerebral palsy. Another was that I felt compelled to do something, however small, to help relieve the suffering and stress on families, which anyone who has any connection whatsoever to disability in Australia witnesses all around them, every day.

Yet another reason was that I felt it was a useful way, however small, of repaying my own family's good fortune in having had access to the UK disability support system for 12 years – access which not only saved my sanity but also left me with enough energy and motivation to fight for something better in this country other than the shambolic, fifth-rate begging bowl system currently in place here. Exposed to the Australian system, many parents of severely disabled children are simply too depressed, exhausted, disheartened and poverty-stricken to do anything much more than drag themselves out of bed each morning and somehow get through the day. Whether by accident or deliberate design, this is probably something for which Australian politicians and disability policy makers give thanks.

By contrast, I returned to Australia fired up with a passion to do something – again, however small and modest – to spread the message that a nation's disability support system doesn't have to be this appallingly bad. That something far better is not only possible, but actually exists in other comparably wealthy, first world countries. With our fund-raising capacities limited, I and the family members who helped me set up Fighting Chance decided to concentrate initially on helping families and people with disabilities pay for the ongoing therapy services which are so essential and beneficial, but which are virtually unobtainable now unless paid for privately.

When I first heard about the proposals for a National Disability Insurance Scheme, while researching a feature article for the Weekend Australian Magazine about the dire state of disability services in this country, I realised immediately that this was, of course, the answer – the grand, imaginative, transformational, conceptual leap necessary to overcome the mess created by nine separate federal, State and Territory disability bureaucracies and a confusing, fragmented plethora of non-government service providers and disability charities.

David and I went into disability exile in 1995, when Shane was five years old. We wanted access to Conductive Education, a brilliantly effective method of helping children and adults with motor disorders, such as cerebral palsy and spina bifida, as well as stroke damage, Parkinson's disease and multiple sclerosis. Although widely available in the UK, New Zealand, Israel, Hong Kong, Europe and

North America, vested interests in the Australian medical and therapy professions had to that point managed to block any government funding or support for CE in Australia, including through a disgracefully biased and deceitful NH&MRC report, released in 1993. In the absence of any consumer choice or control over how funding for disability services is allocated in this country, David and I realised that the easiest course of action for us, by far, was to leave our families, our friends, our jobs and the house we had just built and move to the UK, where Shane attended an excellent CE primary school staffed by conductors, teachers, physiotherapists, OTs and speech pathologists, all fully funded by the UK Education system in acknowledgement that consumer choice is not just something to which governments should pay lip service, but actually put into practice.

After our son was diagnosed with spastic quadriplegic cerebral palsy, in Canberra in 1990, we had been offered one hour of government-funded early intervention physiotherapy every six weeks. One hour every six weeks. Plus one hour of speech therapy every six weeks, and one hour of occupational therapy every six weeks. Each of these three hours was, but of course, on a different day. We knew this was a joke, given Shane's level of disability. The therapists at the early intervention centre in Canberra knew this was a joke. A sort of sick, "we'll pretend to offer a service and you pretend to be grateful" joke. They, and we, knew the service they offered was actually a total waste of taxpayers' money. But like so much else in the Australian disability support system, the game then, as now, is simply to appear to be doing something, to appear to be offering a service. The fact that all too often nothing is being achieved, that actually nothing meaningful is being done, is irrelevant. The system here appears to be based on the belief that it makes good economic sense to squander a small amount of money on maintaining an empty facade rather than investing a decent amount of money on doing something that actually works and is meaningful. It is absurd.

In the UK, by contrast, we were the beneficiaries of a disability support system that actually **is** a support system, rather than some sort of surrealist, Monty Pythonesque nightmare. When Shane needed a wheelchair, for example, we rang our local wheelchair service in a nearby NHS cottage hospital, got an appointment within a couple of weeks, saw an occupational therapist and a wheelchair technician and then collected the chair they recommended, and which the NHS fully funded, a few weeks later. An OT employed by the local council rang **us**, asked if she could assess what equipment we needed in our home, came by a week or so later, went around working out what equipment we needed, ordered it and soon after it was delivered, free of charge, to our door. When it was decided Shane needed to be tube-fed because he was developing swallowing difficulties that could become life-threatening, everything was organised for us, smoothly and efficiently. Boxes of liquid feed and plastic tubing were delivered to our door each month, automatically and free of charge. The special orthopaedic shoes he needed, to keep his feet from becoming grossly deformed, were ordered by the physiotherapists at his school without us even knowing about it until he arrived home in them. Families in the UK who need a wheelchair-accessible car, because they have a family member who uses a wheelchair, get a special mobility allowance which pays for one. When we decided we wanted Shane to go a weekly boarding school from the age of 12 on, because I could no longer cope with being woken four or five times every night as well as trying to work full-time, he was offered a place in an excellent weekly special needs boarding school of our choice more or less immediately. This placement freed my husband up to do a PhD in political science, as well as giving Shane an actual teenage social life and enabling me to continue to work and pay taxes. It meant David and I also had some time to focus on our long-neglected other two children. I could go on and on.

I trust, however, that in the light of all the submissions received and evidence heard to date, Commissioners can very easily grasp how different the UK system is from that currently operating in this country.

Essentially, there are three fundamental factors at play in the UK system that are entirely – entirely – missing from the Australian, and which need to be introduced here if any truly meaningful reform is to occur.

1. First and foremost, access to basic, essential disability support services in the UK, as in many other countries, is a right; a right guaranteed by law. And a legislated right to services on the basis of assessed need has profound implications for how all government agencies involved in disability service provision act, think and behave. If a government agency knows that by law, it must provide a service – that staff just don't have the option of shrugging their shoulders and saying: "Sorry, our budget ran out two months ago; try again next financial year, or maybe the one after that, or better still why not just fund it yourself, or else go beg some charity for help?" - then that agency has all sorts of incentives to spend its budget as efficiently and cost effectively as possible; to make available funds **last**. And that means actually reducing the paperwork and the red tape and the messing around to an absolute minimum, because paperwork and red tape and messing around **cost – and waste - money**. The incentives in the viciously, indiscriminately rationed Australian system work in entirely the opposite direction, which is perhaps the single most important reason the current system is so deeply, deeply dysfunctional.

2. Almost as significantly, a legislated right and entitlement to the provision of basic and essential services fundamentally alters the power balance between service providers and service consumers. Individual consumers will of course always be, to some extent, at the mercy of providers and funding bodies and the often very difficult decisions that have to be made, given finite public resources; the capacity of lone individuals to determine how public resources are allocated in highly complex systems will always be limited. It is pie-in-the-sky to think otherwise. But individual consumers have **no power whatsoever** if and when they are placed in the role of cap-in-hand supplicants, thereby being made to feel as though they should be grateful to get anything at all - on the off-chance they do. In the UK, entitlement to funding on the basis of assessed need puts each individual with a disability at the centre of the finding process, which is precisely where each individual with a disability should be.

3. The UK system is co-ordinated, integrated and well planned, on a whole-of-life basis. It recognises that since a two-year-old with autism or Down syndrome or cerebral palsy, for example, is still going to have autism or Down syndrome or cerebral palsy when 20 or 30 or 40, given current medical knowledge, then it makes simple common sense to plan services on a long-term, whole-of-life basis. The UK system gives every appearance of having been designed by people who understand the needs of people with disabilities and their families, through all the different life stages. To an Australian, this is quite astonishing. Arrangements often start to be put in place for the next phase of a disabled child's or young adult's life even before families themselves have started to think about that next phase. When Shane was 17, the local council's children's services social worker began the process of handing over to the adult service social worker, who dropped by for a cup of tea and said to Shane:

> "As you'll be turning 18 soon Shane, you need to start thinking about where you want to live; whether you want to keep living at home with your mum for the time being or move into independent accommodation, which you have a right to do once you become an adult". Can anyone even begin to imagine such a conversation happening in Australia? Here, by contrast, we have a system that gives every appearance of having no intelligent design whatsoever, if not actually designed by a sadist. When I applied to the NSW disability equipment service for a couple of basic pieces of equipment, for instance, the entirely useless and maddening reply I got was: "Good news, you meet the eligibility criteria, but bad news, our budget ran out three months ago. If your son really needs a shower and toilet chair so desperately" [*which oddly enough, he did, since going to the toilet and being able to have a shower from time to time are not really all that optional]* - "have you thought about applying to a charity?" This was a suggestion which did not actually appear to me to fully justify that public servant's taxpayer-funded salary.

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Based on the assumption that this Inquiry is by now all too fully aware of the many problems with Australia's current disability support system, and needs no further examples from me – although I have thousands! - I'd like to present what seems to me to be four requisite steps towards a solution.

1. **Get politicians – and politics – as far away from the process as possible**

   Exhibit A: *"Stronger Together. The next five years – a consultation paper"* , June 2010, prepared by the NSW Government's Department of Human Services, Ageing, Disability & Home Care Section.

   Nobody reading this document, with its cheery, self-congratulatory foreword from Premier Kristina Keneally, would have any idea that despite significant additional funding over the first five years of Stronger Together, the NSW disability support system remains in crisis after decades of severe under-investment, with 1,000 people alone on the register of urgent need for supported accommodation services, but without the slightest prospect of accommodation ever being made available for the vast majority. Instead, ageing parents will continue to be expected to just carry on, into the 70s, 80s and even 90s. In NSW, as elsewhere around Australia, not even the fact of an ageing parent developing cancer or multiple sclerosis is enough to ensure that a supported accommodation placement can or will be found for a severely disabled adult son or daughter.

   As long as most disability services continue to be funded out of State budgets on an arbitrary, year-by-year basis, then numerous harmful political incentives remain for government ministers and senior bureaucrats to ignore and/or hide and/or remain in denial about levels of unmet need – however desperate and destructive of individual lives this ongoing failure to meet basic needs may be – and to paint as rosy, glib and dissembling a picture as possible.

This comment is not meant to single out Premier Keneally or the NSW Disability department for any particular criticism; indeed, in my view the NSW Government is to be strongly commended for the efforts it has made through Stronger Together to introduce longer term planning and improve services. But, as the architect of Stronger Together, former DADHC Director-General Brendan O'Reilly, himself said (with highly unusual candour) to a public meeting in February 2009, this problem is now simply too big for State governments. Australia needs a transformative national disability insurance scheme, funded at least in part by a compulsory national insurance levy.

Australia's disability support system, I believe, needs to be taken out of the mainstream political process and placed in the hands of an independent national body, similar to the Health Insurance Commission which administers Medicare, funded by:

- contributions from each State Treasury on an agreed, ongoing per capita basis;
- a compulsory "insurance premium" paid by taxpayers, structured progressively in the same way as the Medicare levy; and
- top-ups from federal government funds.

Although answerable and accountable to federal Parliament and therefore ultimately all Australians, such an organisation would be able to function relatively independently of the rough and tumble of day-to-day political, resource allocation processes, as is the case in the UK and other countries where access to essential services is a right, not some obscene sort of lucky dip. A national Disability Insurance Commission could move far more fearlessly than politicians are understandably able or willing to do to quantify – and most importantly, *reveal* – true levels of need in the many areas of disability support services. Given that resources are finite, and obviously are always going to be finite, then such a body could more openly set priorities, on short, medium and long-term bases, and decide on the basis of analysis, data and research what was and was not to be funded, either wholly or in part, as the Health Insurance Commission currently does in relation to the level of Medicare rebates and Medicare-funded services.

### 2. Abolish all current funding allocation models

Currently, most federal funding for disability service provision goes to eight discrete State and Territory disability departments to administer/dole out, alongside funds allocated by the eight State and Territory Treasuries. Each of these eight discrete State and Territory disability departments has its own resource-consuming bureaucracy of directors-general, deputy directors-general, assistant directors-general etc etc etc – as does the federal disability bureaucracy.

In turn, a significant percentage of the money administered/doled out by federal or State bureaucracies goes currently in block grants to a plethora of non-government disability service providers, each also with *their own resource-consuming administrative bureaucracies* of CEOs, deputy CEOs, assistant CEOs etc etc. Although block grants are to a considerable extent tied to certain specific purposes, such as therapy, respite, accommodation and so on, non-government service providers retain considerable power in deciding what sort of therapy services to offer, for example, or what sort of respite, or what sort of supported accommodation services.

Significant resources are further expended by the requirements for non-government service providers to report back and account to State, Territory and/or federal disability bureaucracies each year for the money they have spent. Still more resources are expended by State, Territory and federal disability bureaucracies meeting among themselves.

By the time all this money – billions of dollars each year - is filtered down, and up, and around, and down again, through all these layers and layers of bureaucracy, red tape and middlemen, there is not a great deal left for actual on-the-ground service provision for people with disabilities and their carers, who are of course currently at the very end of the funding allocation food chain.

Furthermore, non-government service providers currently have as little incentive as politicians and bureaucrats to **reveal the truth** about levels of unmet need and the numbers of desperate people they are forced to turn away each year, because they are now so reliant on government funding. Fundamental organisational self-interest and self-preservation dictate that non-government service providers play the tune demanded of them by politicians and government bureaucrats, at least in public, which means lots of gloss and spin and very little hard cold reality which in any way might embarrass the government of the day. Championing the interests of disempowered, end-of-the-food-chain service applicants by openly revealing and condemning severe shortfalls in government funding for basic disability service provision is not, as a general rule of thumb, on service providers' agendas.

This is a very sad and regrettable situation, since many of Australia's non-government service providers were actually started by parents and/or people with disabilities, and had a proud history of outspoken advocacy before changing, sometime around about the 1980s, into more or less forelock-tugging recipients of government funding.

### 3. Introduce a far more direct, person-centred funding model, based on a legal entitlement to basic, essential disability service provision

While an independent national funding body with an extensive network of regional offices around Australia would of course have its own administrative overheads and running costs, there would be one streamlined, co-ordinated government disability bureaucracy – not nine as at present.

If funding were to be assessed, and allocated, on an individual basis, according to the level and nature of each eligible individual's disability, a vast amount of middleman bureaucracy would immediately be eliminated. Over time (given this would inevitably involve a gradual process) power relationships would be transformed, with many adults with disabilities and the parents of children with disabilities newly and significantly empowered to make the decisions as to the nature and type of services they wanted, and from which service providers; not government and non-government service providers still paternalistically making those decisions for them, with only the lightest lip-service paid to "consultation", "consumer feedback" and "self-determination".

As an intelligent, well-educated mother of a son with a severe disability, I am personally sick to death of being in an entirely disempowered position when it comes to decisions as to what is in my own son's best interests; I would much prefer it if I and my now-adult son got at least some say in deciding how any funding available to help meet his care and support needs was spent, and on what, and many other people with disabilities and parents feel precisely the same way. Should people with disabilities or the parents of children with disabilities not wish for whatever reason to make those decisions, but prefer that their funding continued to be allocated to and handled by a service provider, then fine. Whatever the decision, the most important thing is that the decision should be theirs to make.

## 4. Break the toxic nexus between intervention and rehabilitation services and the medical model of disability

Because of its rigidities and almost complete lack of consumer choice and empowerment, Australia's disability care and support system remains far too much in the extremely old-fashioned grip of the medical model of disability.

Traditionally, disability has been seen as primarily a medical issue, with medical professionals alone having the expertise to assess and influence what the impact of any particular disability on a person's future functional skills and abilities will be. But because medicine can as yet do nothing to "cure" many types of disabilities – only, at best, manage symptoms - the medical model tends as a direct result to be innately pessimistic, negative and defeatist.

Ask any parent of a severely disabled child how the doctor who diagnosed their child's disability broke the news to them, and you will be told, over and over and over again, that the doctor hit them with a gloomy litany of all the things their child would "never be able to do" – never walk, never talk, never be able to feed him or herself, never even be able to operate the controls of an electric wheelchair, and so on and so on.

While there are of course exceptions, and attitudes of late may well have changed, the vast majority of parents of severely disabled children will recount that the advice they received from the diagnosing doctor was essentially: take this child home, don't waste your time trying to make any difference because it's hopeless, just focus instead on your other children and get on with your own life. Similarly, therapists operating within a medically based framework – physiotherapists, occupational therapists and speech pathologists – tend to have very limited, low expectations of a severely disabled person's physical capacities and potential for improvement.

Since expectations so often shape outcomes, a pessimistic approach is all too often a self-fulfilling prophecy. Expect little if anything, act accordingly, and the chances are overwhelmingly high that outcomes will be exactly as poor as predicted.

An alternative way of thinking about disability is not to regard it as a medically incurable condition but far more optimistically and positively as a developmental challenge, with significant developmental progress – certainly far beyond any medically based predictions – able to be made, given the right type and intensity of specialised intervention at the right time.

I believe this is an issue the Productivity Commission should explore in more depth, given the potential of many intervention approaches outside the generally pessimistic and defeatist medical mainstream to reduce the long-term impact and costs of disability. I hope for instance that Commissioners may take the opportunity presented by the forthcoming visit to Australia of Canadian psychiatrist Dr Norman Doidge, author of the groundbreaking book *The Brain That Changes Itself*, to seek his expert views on this matter.

My chief aim in this context, given limited space constraints, is to point out that many parents of children with disabilities have long rejected the advice of doctors to, in effect, “forget it; just write this child off”. And as a result many parents - such as Cheryl Koenig, whom I gather is also giving evidence to the Commission - have achieved remarkable results, far beyond doctors’ predictions. The central point I wish to make here however is that in my experience, the disability support system now in force in Australia actively hampers and discourages optimistic, innovative intervention methods outside the reaches of the medical mainstream. With few exceptions, parents wishing to access alternative methods have to pay tens of thousands of dollars to travel overseas, or to bring overseas-based practitioners to Australia and establish and run their own centres, as a small group of us parents did when we established, ran and funded a Conductive Education pre-school in Canberra in the early 1990s. The response from a senior ACT disability bureaucrat with a physiotherapy background to whom we went, cap-in-hand, begging for some modest funding, was to assure anyone who asked that we were “a sad little group of mothers in deep denial and unable to come to terms psychologically with their children’s disabilities”.

Any truly transformational move towards individualised funding and consumer empowerment must be flexible enough, I believe, to enable adults with disabilities, and the parents of children with disabilities, to access therapy and rehabilitation methods that are commonplace overseas, but which have barely been able to gain a toehold in this country.

The classic Catch-22 argument used by the medical profession to date to block any public funding for alternative approaches – that these approaches cannot be publicly funded until their efficacy has been thoroughly researched, but no centres should be funded to enable research to be conducted until efficacy is proven – must be seen for what it is: vested professional self-interest of the worst possible kind.

Apart from anything else, the lack of alternative approaches has meant that little if any pressure has ever been exerted on medical-model intervention services to demonstrate *their* efficacy. The development of alternative models of educationally based intervention and therapy services will, for the first time, enable, encourage and facilitate much-needed research into efficacy and outcomes.

Any disability support system that is based around long-term, whole-of-life planning will by definition place considerable emphasis on good quality early intervention and therapy services. That's because good quality early intervention and therapy services help to reduce the long-term impact of disability, thereby saving a lifetime-focused disability support system a great deal of money over time.

At our Conductive Education pre-school in Canberra, many of the children, including Shane, were toilet-trained. Nobody in the ACT Government-run early intervention centre had the slightest interest in doing this, let alone the expertise. Young children there were, and I bet still are, simply left in nappies, where they remain their entire lives. Yet a lifetime's supply of nappies costs a small fortune. Do government-run or funded early intervention centres in Australia care about this long-term cost? Of course not. Not their problem.

However, after several centuries of what Dr Doidge has labelled "neurological nihilism", even the most conservative backwaters of the medical profession are now coming to acknowledge that the human brain has an astonishing capacity to recover from injury. This is due to something called neuro-plasticity, which the mainstream medical profession insisted up until about 10 years or so ago didn't exist, but which it is now getting highly excited about. As a result, the importance of early and, ideally, intensive intervention after a brain injury is now becoming more and more understood and accepted. The principles and practises of Conductive Education, for example, first expounded some 50 years ago in Hungary, are based on an instinctive understanding of plasticity and its potential.

Yet in this current climate, what is happening in Australia in terms of early intervention and therapy services today? Apart from the early intervention initiative for pre-schoolers with autism, pretty much nothing really – literally. The deterioration in early intervention and therapy services over the past 10 years or so has been truly shocking, and runs counter to all the latest medical thinking and research into the brain's capacity to form new neural pathways despite even extensive damage. The savage cutbacks over recent years in what were already minimal early intervention and therapy services are indicative of a disability support system that is in terminal, end-stage meltdown, strangling on its own red tape, inefficiency and poor design, simply lurching now from crisis to crisis, with panicky politicians throwing good money after bad in knee-jerk responses to whichever disability group manages to get some publicity.

Australia's current disability support system must not be reformed, or re-shaped, or expanded. It must be scrapped altogether, and redesigned from first principles, from the foundations up.

Those who argue against the creation of anything like one new national Disability Insurance Commission, on the grounds that it would have too much centralised power and/or control over the lives of people with disabilities and their families, seem to me to miss the absolutely basic, crucial point: that if billions of dollars of taxpayers' money are to be expended on disability support services – which they will and must be - then there has to be some form of administrative body, answerable to taxpayers through Parliament, to allocate that money. No model is perfect, of course, but in the real world, some sort of intermediary funding agency has to exist and make decisions as to resource allocation, and one national agency seems to me infinitely preferable to nine fragmented federal, State and Territory agencies. If access to basic essential services and supports are guaranteed by law, then the capacity of any government agency to "bully" or cost-cut, or any of the other concerns raised by other submissions to the Productivity Commission, is by no means eliminated, but it is significantly reduced. An independent Appeals Tribunal mechanism would further assist to protect the interests of people with disabilities and their families/primary carers, as occurs in the UK .

**How it might work**

- Once a person has been diagnosed by a medical professional as having a permanent disability that restricts his/her capacity to live independently and/or without the aid of mobility and other disability equipment, then that person should be able to go to the nearest regional office for a detailed assessment of current and future needs. This client should be assigned a liaison officer/case manager who should open a file that will remain a single, central reference point for the rest of his/her life, obviating any need for a person with a disability or family carer to go through the same background details over and over again with every new service provider and/or medical professional.
- On the basis of standard actuarial charts as currently used by Australian courts, an assessment would be made as to each individual's long term care and support needs in the areas of: early intervention and ongoing therapy; equipment; schooling supports if relevant; post-school options; respite; leisure and social activities; home modifications; and accommodation. A sum of money should then be nominated, to be held "in trust", so to speak, by the national administering body and only released as necessary to pay for listed services and/or equipment. Wherever and whenever possible, the client and his/her primary carer should have the right to choose where specifically and on what that money is spent.
- All information as to available and appropriate services, service providers and equipment should be centralised in one place, thereby eliminating the need for people with disabilities and their carers and/or families to dig around as at present, often stumbling on appropriate service providers or helpful equipment by sheer fluke.

Such a system would achieve certain fundamental improvements and benefits, in my view.

Post-diagnosis, it would give people with disabilities and their families considerable, vitally important and beneficial peace of mind, knowing that whatever other challenges they faced, their most basic, practical support needs would be covered, for as long as necessary.

A long-term, whole-of-life perspective would automatically mean that far greater emphasis would be placed on providing services and equipment in a timely and efficient way - because this saves money over time. Making a person wait three or four years for a wheelchair that supports their body properly, thereby minimising the risk of painful contractures and deformities, is not just a cruel but also a false economy. A long-term, whole-of-life perspective would also encourage far greater interest in good quality, effective early intervention educational and therapy services – because enabling people with disabilities to reach their full potential and reduce their level of dependence on others saves money over time.

Annual lump sum allocations for therapy services, for example, would give people with disabilities and their families far more choice and control over which therapies they accessed. Over time, comparative research into the efficacy and cost-effectiveness of various therapies could also be properly undertaken, and the results published to enable people with disabilities and their families to make more informed choices than is possible at present.

All service providers would have to start offering consumers services that they wanted and were happy with, because otherwise, consumers would be in a position to vote with their feet and go elsewhere – unlike the situation today where too often, services are offered by providers on a "take it or leave it if you can even get it" basis.

Non-government disability service providers would also be freed up from the burdens of constant charity fund-raising to cover basic service provision, enabling them to concentrate more on specialised, quality service provision, as occurs in the UK.

Finally, so much of the current waste and inefficiency and lottery-like inequity would be eliminated. It is beyond galling to find yourself in the position of desperately needing help from a system which employs multitudes of people to decide there isn't enough money to provide that help. No one should be employed in the Australian disability support system in order to turn people with disabilities away and refuse them and their families services; they should only be employed in order to assess eligibility, and then facilitate service provision for eligible individuals.

It's all too easy, I do appreciate, to describe an effective, efficient disability support system in sweeping generalities. The devil, but of course, is in the detail. How one defines "eligible", where lines are drawn and cut-offs delineated, is just one of numerous contentious issues.

But in very general, first principle terms, I would like to see a system in Australia where funding for disability service provision attached FAR more directly than at present to the person with a disability and where applicable, his/her family carers. This will of course need to be phased out gradually, but government funding should not go directly and solely to service providers to decide how, what and on whom that money gets spent. It should be allocated directly to people with disabilities and their families, or to a nominated agent, to decide from which service providers they wish to purchase services. By guaranteeing insurance cover for each individual affected by lifelong disability, a National Disability Insurance Scheme would facilitate that sort of transformational approach to resource allocation.

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In conclusion, I am almost as horrified as an ordinary taxpayer by the waste and inefficiency I have encountered in the Australian disability support system as currently designed as I am as the mother of a son with cerebral palsy.

Clearly, what needs to be put in place in Australia, as a matter of the utmost urgency, is a disability support system that eases the grief and the pain and the stresses of disability – not exacerbates them. If we are going to have a disability support system at all, then we should ideally have one that works as smoothly, efficiently and cost effectively as possible to meet people's needs within a long-term framework – not one that blocks and impedes and frustrates, wasting so much precious time and energy and money.

Like many other Australians, I want to see a disability support system that invests wisely (i.e. from a long term perspective) in people with disabilities and their families, giving all those of us affected by disability the capacity to reach our full potential and contribute as much as possible to society; not one that so often immeasurably worsens the initial level, degree and innate stress of disability, and which thereby, in the process, has the unintended but entirely predictable consequence of disabling whole families.

No system is or can ever be perfect, of course, but a decent, reasonably efficient, reasonably effective disability support system is not a pipe dream, nor is it rocket science. It just requires everything that the Australian disability support system has so far lacked, and lacked abysmally: proper design and planning, national level co-ordination, adequate funding, clear cut goals and objectives, and intelligent leadership.

There is no lack of compassion in Australia. There is no lack of effort, nor good intentions. But good intentions are not enough. The road to hell, as the Australian disability support system demonstrates only too clearly, is paved with good intentions. And hell is where too many Australians with disabilities and their families have found themselves; hell is where too many of us live right now.

Sue O’Reilly

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