# Submission on the Productivity Commission’s Draft Report on Disability Care and Support

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## Background

I am a person with a physical and neurological disability and have been a wheelchair user since December 2008. I am also hearing impaired. My Drs are still not fully aware of the cause of my disability but they are suspecting that it may be genetic. I have been trying to get a diagnosis since July 2008. I have formally been diagnosed with Dystonia which is a neurological movement disorder that has left me a wheelchair user. There is no cure and it has various causes from a genetic primary condition to secondary to another disease or disorder such as MS or MD.

My husband, Jeff has been my carer since July 2008 and is still in full time work. Prior to becoming a wheelchair user I worked as a support worker for people with disabilities and I have completed TAFE certificate 3 in disability studies. Ironically since July 2008 I have needed this help myself.

Because I have had such a difficult time getting a diagnosis I have been stuck under Domicilary Care SA (HACC) services. They only provide 2 showers a week and equipment. I have applied to Disability SA once and have been rejected and I am currently awaiting their reply to see if I now qualify for services from them instead of Domiciliary Care. The only reason why I was ever accepted into the HACC services provided by Dom Care was because in 2008 all I knew was that I had a chronic condition called Fibromyalgia and also chronic fatigue syndrome. These are considered medical conditions NOT disabilities yet there are thousands of people with these conditions in Australia who are not entitled to any support, despite the fact that they can sometimes be completely bed-bound or become a wheelchair user because of their condition. Now I know that Fibromyalgia (and chronic pain and fatigue) is not the only cause of my disability which is why I have applied again for services from Disability SA in the hopes of receiving more than 2 showers a week! I have heard that HACC services may be going to be reformed to only have clients who are over 65 and what I am wondering is if someone is not eligible for NDIS or NIIS and they are under 65 and there is no HACC funding or no other funding to support them would these people just miss out?

My husband and I spoke at the hearing last year and also did a submission which is no. 104 on the internet. We are both fully supportive of the National Disability insurance scheme both from the perspective of a person with a disability and a carer of a person with a disability.

We make the following comments suggestions based on the overview and recommendations draft report.

1. On page 12 it says that people with bad backs and other musculoskeletal conditions should not be included and that people with mental health problems should also not be included. Like I said in the background section, I entered DomCare with an acknowledged condition fibromyalgia, but a knowledge that there was something far worse going on. Fibromyalgia comes under the bracket of a musculoskeletal condition. My fear is that there would be thousands of people missing out because of they come under the bracket of musculoskeletal. I think the idea of this being only for people with severe to profound disabilities is also unfair. I think that the NDIS should be for anyone regardless of age, diagnosis, disability, whether they have a mental health condition or whatever. It should just be for anyone at all who needs assistance. The NDIS should be needs based rather than diagnosis based. The report says different things about this aspect in different places – just as long as everyone who needs assistance gets it that's the way I think it should be.

My personal view is that care should be taken to act on the principle (ie that the NDIS would not cover people who would be better treated elsewhere) and not the example. There is justification for people with **specifically** musculoskeletal conditions to rely on the health system. However, many disabling conditions have musculoskeletal aspects – I would expect that anyone who has a mobility problem probably has it because their skeletal muscles don't work as they should, but that is a symptom, not necessarily the only cause. The skeletal muscles of sufferers from cerebral palsy, for example, don't work as they should – but the underlying cause is a neurological one.

As for dedicating the NDIS solely to "severe and profound" conditions, I take the slightly milder view that it is a question of definitions. I understand that "severe" and "profound" are terms of art in disability work and describe levels of severity of conditions. If this is the case, then an NDIS which is based upon need (as I believe it should be) should use other terms which can be unambiguously defined. On the other hand, it begs the question as to whether such a differentiation is required. My wife needs a wheelchair with certain features, but she can cook for us with limited assistance – does it matter, for the provision of that wheelchair, whether her condition is "severe", "profound", "mild", "catastrophic" or whatever? If she has to be classified thus, should she be treated the same as someone whose condition is of a similar severity but who cannot cook for themselves?

The other thing on page 12 is about tier 2 people being referred on but I am wondering where would they be referred to? The report states that Tier 2 people will be provided with linkages to "relevant services … such as mainstream services and community groups”. I think it is important that there is a “safety net” for the (possibly rare) cases that such services are not immediately available to a particular individual, and that there is a mechanism for referring individuals to Tier 3 if their needs increase.

I hope the information service is better than the current one because they knew nothing to help me I had to find it all out for myself!

2. I also question the whole permanent vs non-permanent because there are so many conditions that are considered long term. When does long term become permanent and what is the difference? The only people who may not be considered for NDIS would possibly be people who for example break their leg its what 2 months in a cast and then some physiotherapy. That kind of short term injury that is minor should be covered under the health system but everything else should be totally needs based. Take Fibromyalgia and chronic fatigue syndrome for example. There are people who are completely bed bound with these conditions who cannot even sit up for 5 minutes a day. Yet there are other people who walk without any aids do all their personal care themselves. That is a huge spectrum. Just cause someone has an eligible condition does not mean that they should or would apply. The other interesting thing is that with the Disability support pension eligibility (I talk more about DSP later) it includes chronic fatigue syndrome as a eligible condition and a Disability YET it is considered a medical condition and people with these conditions are not eligible under the current disability scheme in SA.

Again this is a question of definitions. Where do we draw the line between long-term, medium-term and short-term? Unlike “severe” and “profound”, I believe there is some justification for drawing this line. It would be wasteful to custom-design and build a wheelchair for someone whose condition is only temporary, even if it will last quite a long time (though a time will come when it is too long). I think the line would best be drawn by direct consideration of needs rather than a standard prognosis for various conditions. One worthwhile approach might be to treat conditions which have the potential to be short-term as temporary while standard interventions are tried; if these initial interventions fail, the condition may be upgraded to medium- or long-term.

3. We believe that the NDIS instead of being separated at pension age there should just be one system for everyone regardless of what their disability is. It is simply too complex to have lots of different systems and making people change systems at 60 or whatever. I believe that realistically if you need help when you are over 60 you basically have a disability while it may be aged related and not acquired genetically or by other means it is still a disability. For example, if someone cannot walk and they need a wheelchair, personal care assistance, cooking, cleaning assistance etc there is not much difference between being 30 and needing this and being 90 and needing this type of help. The main difference between a 30 and a 90 year old is one is just starting out in life and

one is near the end of their life so they would have different goals. So if the NDIS is as individualized as it says it will be then this sort of thing will be covered. For example the recreational activities that a 30 year old wants to participate in would quite probably be different from a 90 year old. (page 15) On the other hand this may get too large and be too hard to run. I can see that perspective as well. I guess the main thing is to not have people with disabilities reaching 60 and then having to fight for the services they've had for the whole of their lives all over again

4. Touching on the last two items, I think it important that all people, regardless of age, have the right to the benefits of the NDIS. At the same time, people above a certain age should be eligible for the benefits applicable to aged persons, on the same terms. If this includes a means-tested co-contribution, so be it.

5. It can take some people up to two or more years to be diagnosed especially when a genetic condition is suspected. Genetic conditions do not have to occur at birth some can occur at any age. I am in this situation and are currently being treated by a geneticist to see if I have Mitochondrial disease which is a group of 400 diseases under the bracket of Muscular Dystrophy. This may take up to two years according to my Dr to be diagnosed. So that's why its important for the NDIS to be needs based then it doesn't matter what your diagnosed with you know that you will be covered by the scheme. Its important that if people are in the process of obtaining a diagnosis then they are still eligible for services.

This highlights the necessity of a needs basis rather than a diagnostic basis. A diagnosis base serves only to use the limited resources of medical specialists, who frequently (in my experience) have long waiting periods. Further, a diagnostic error in the first instance can have long-term repercussions, in part because (again in my experience) doctors tend to follow the diagnoses of previous doctors.

6. I don't think it's a good idea to have an independent assessor to determine eligibility because it is a double up! Why should there be an outside assessor who knows NOTHING about the person with a disability when their GP who knows them well can do it? Sure there would have to be training for this but it seems a waste of money and a double up. This occurs all the time in the current disability system! (page 18-19)

When we spoke at the NDIS consultation in Adelaide I heard what the basic process was aiming to be like from one of the commissioners and honestly I was taken aback. IF it is as good as they said they hoped it would be (if the NDIS is agreed to by the Government) it would be like a dream in comparison to the disability system now. They explained to me that I would have  a say in what I thought I needed such as a wheelchair and other equipment x amount of support hours and that the independent assessor would basically be there to make sure I wasn't a fraud or asking for an $80, 000 wheelchair when a $8, 000 would do kinda thing.

I agree, though I can understand the inclination toward an independent assessor: the NDIS budget could blow out if there is a real equivalent of "Dr Howlong" who gives patients what they want regardless of the facts. However, it seems to me that if a particular doctor has a large number of patients using the NDIS then an audit can be carried out. In such cases I do not think NDIS benefits should be delayed by the possibility of fraud (or laziness) on the part of the treating doctor.

7. There are so many different types of disabilities so the assessment "tools" that are referred to on pages 18 and 19 would have to bear this in mind, eg a person with an intellectual disability in comparison to one with a physical disability has completely different needs and often the assessment tools are generic and used for any disability and I have filled them in thinking that this is a bit irrelevant to me.

This is an important point requiring vigilance to ensure that the scheme retains its needs basis. Statistics have a slippery way of starting out measuring things which are important, and ending up giving things importance because they can be readily measured.

8. It is fine that the NDIS has boundaries however the health and disability systems need to be linked. The problem at the moment is that they don't talk to each other meaning that people are stuck in hospitals longer than they need to be. So there needs to be good communication between the NDIS and employment, education, health and whatever other departments are involved.

Specifically, the system should be arranged so that poor communication between departments should not affect benefits. This may involve NDIS officials actively advocating on behalf of beneficiaries, or assisting them to advocate for themselves.

9. Income support such as the DSP should be outside the NDIS. I think all the talk of people with disabilities should be working and they shouldn't be on DSP is just awful. I mean quite honestly if an employer had a choice between a person with a disability and an able bodied person they would most likely choose the able bodied person. There are so many factors on why people with disabilities are not always working whether they are able to or not. It makes me angry because we have to fight to get just about anything and then we are criticized for being on DSP!

   If a person is unable to do their own personal care, cooking, cleaning etc plus the consideration of transport issues (eg access taxis that do not turn up) plus making a workplace accessible plus the fact that many people with disabilities have a lot of medical appointments etc the reasons go on and on.

I don’t think that people with disabilities are lazy just because they are on the DSP. There are so many disincentives like if you do too much work (like more than 15 hrs) or if you have a partner who earns too much money plus the money you earn while working then the DSP drops. It’s not just an income, it’s also the pension card (like getting bulk billed by doctors, getting subsidized prescriptions, concession tickets, help with audiology costs, subsidized utilities and council rates) all these things add up and help with the costs of daily living.

The costs associated with a disability are far greater than for the average person. The person with a disability should be able to have a choice whether they work or don’t work but should not be forced into job network program if they do not want this. I never found my employment service to be that helpful. They really had no idea of my needs to do with my disability (and that was before I was a wheelchair user). I think a lot of people on the DSP live in fear that it will be taken from them for whatever reason.

The other problem is that where are all the jobs? I mean if the average person can’t get a job easily then how will people with disabilities do this? There are just so many barriers. I do not think it is a bad thing to work even though you have a disability but unless you are supported in all areas to do this then I cannot see how it would ever happen and peoples attitudes also needs to change (such as employers).

I agree that income support (eg the DSP) should not be part of the NDIS. However, I think that many things which are DSP-dependent (eg the Health Care Card, audiology subsidies, PBS benefits and the like) could be better covered by the NDIS at the risk of increasing costs attributed to it. At present, by the magic of effective marginal tax rates (EMTRs) I lose half of every dollar I earn over my normal salary – 30% to increased income tax and 20% to a reduction in the DSP. If Erin got a job of over 15 hours per week, she would lose the DSP and all its other benefits – and she would need far more than an entry-level job to justify that. Even if she got a job working less than 15 hours per week, we would lose at least 40% of every dollar she earnt, even without taking her income tax into consideration – 20% reduction in DSP and 20% off my dependent spouse tax offset. There are mechanisms to remove the effect of EMTRs, but they are outside the scope of the NDIS.

Further, if she earnt about $600 in a fortnight (about equivalent to $15600 pa, a relative pittance even if she only worked less than 15 hours) she would lose the entire pension, which with all its associated benefits just isn’t worth it. Tying these associated benefits to the NDIS rather than to the DSP would give a greater incentive for people with disabilities to find work.

10. I spoke of double ups earlier and I am wondering with the individual support packages whether if someone already has a private physiotherapist for example would they have to use a NDIS physiotherapist (or occupational therapist) for example if they were being assessed for a wheelchair? Because quite honestly I am currently being evaluated for a wheelchair and there are so many people involved creating a double up. There is the physiotherapist from Domiciliary Care, the physiotherapist from the wheelchair clinic AND my private neurophysiotherapist. So why does there need to be another physiotherapist involved who does not know me? I think that if someone already has a physiotherapist who is treating them they should be allowed to choose to use them. (page26)

Point 6 above refers. It is understandable that an independent assessor would be desirable to avoid fraud, but I believe that a treating doctor should be able to be used.

11. I think it is unfair that there are unpaid family carers or volunteers from the community. While I understand that these supports would do something regardless of if the person had a disability or not (such as a husband and wife sharing the domestic duties in a marriage so therefore if one has a disability the other would have helped anyway sort of thing) but what I think is cruel in the current system is that these "natural supports" are doing FAR more support than the actual support from the system. Why does the respite centre do over double the help of domiciliary care in our situation? It makes no sense whatsoever. I think it should be basically the other way around with the respite hours being the same (they are doing about 4 hrs a week only until the end of June).

It is certainly nonsensical that a "respite" organization should do more than an official care organization. I think there are two reasons why this has occurred: one, Erin has pursued avenues of help quite doggedly and finally found some; and two, Domiciliary Care have a standard two showers per week (which I do not think has been acceptable in Western society for a few centuries now), three if the patient is incontinent – unless for some reason DomCare don't want to give them a third shower.

12. I think that respite services should be more adequately funded and that there should be more of the consumer directed packages that have recently been trialled we were lucky enough to be able to trial a package like this. Carers get worn out especially when they have to work all day and then look after their partner who has a disability all night! It's just totally unfair on them especially when they have their own medical conditions.

I think there are two problems with the funding for Domiciliary Care:

   a. It seems there is a certain amount of funding available, which has to be stretched as far as possible – hence a minimal standard of care which isn't always provided. For example, I understand that

Erin is entitled to two hours a week of personal care including showering. If the showering is finished in 45 minutes the carer is out the door.

   b. It appears that the staffing level is also minimal, so from time to time (actually quite often) they need to subcontract to agencies, which presumably generates its own overheads for agency administration and casual loadings. A properly funded NDIS would overcome this by employing more of its own staff (see next point).

13. In our first submission we suggested that currently in SA there are over 100 small agencies that provide the actual in home support. I am wondering if it wouldn't be more economical though less choice if some of them joined together or if there was only  a few agencies in each state? Choice is important I understand that but I do think it is a bit silly having over 100 small agencies all under Disability Services SA. It is very frustrating with Dom Care that they are only one agency and that there is no where else to go to so I can see that having more than one is definitely beneficial but to have over 100 agencies its just ridiculous.

14. I think there should be some minimum qualifications for a disability support worker (such as cert 3 disability studies) I don't understand why this is in place for aged care but not for disability. While I understand that some people have been using the same support workers for years who do not have this qualification I think it would be better if it existed. I say this because when I was a support worker I had no idea about anything and didn't really understand disability until I acquired one. At least if I had had more training then perhaps I would have felt more confident in the workplace. This being said I did have some training repeated every year such as bowel care, medication awareness, first aid and manual handling. I can understand that if someone has had the same carer for years its unfair to make them go out and do a certificate but on the other hand I think its actually dangerous that friends and family who are someones carer do not have the manual handling training required to be safe. If they were a paid support worker this would come under occupational health and safety but cause they aren't actually a paid worker its like the government don't worry about their safety or the person who they are caring fors safety either. When in fact if the carer becomes injured then they would be then be reliant on the health and/or disability system. So for safety it makes sense that anyone working with people with a disability have some kind of training. This being said a lot of disability work cannot be learnt from a book. (39)

I think that beyond a basic knowledge a good attitude is more important. It is good to have well-qualified carers, but if we consider the future of the NDIS we need to get new staff in on the ground floor without a long period of training, and we need to stop them leaving for more remunerative employment elsewhere. On the other hand having staff stuck in the same job for extended periods can affect morale. Perhaps work could be done on improving staff morale?

15. I am wondering about funding to providers and agencies such as the Muscular Dystrophy association or Arthritis Australia? Organizations that provide some services but not in home services free to their clients? These organisations play such an important role in people's lives.

    Perhaps they could enter into contracts with the NDIS?

16. I think that the NDIS needs to be implemented as quickly as possible. The system as it currently is, is totally NOT working and people are thinking "is the NDIS for real or is it going to be another promise that will never happen?" While I realize these things take time to implement there should be some way to fund the current system until the NDIS is implemented. Everyone is going crazy waiting for things to change. 43

17. I am very glad that self directed funding and individualized packages are going to be available through the NDIS. People with disabilities (and their carers) should get choices about everything just like the rest of the population does. It's very annoying when the care agencies say we will shower you between x and x time as if you don't have anything else on during the day. What about people who would prefer a nighttime shower but need help getting dressed? Do we have to have a morning shower just because the agency stops working at 4pm? Does our disability stop on the weekend/public holidays such as Easter and Christmas? Supports need to be available when the person wants them, not when they are told they will be having them.

I can see the agency's point that they need to use staff efficiently by avoiding penalty rates and so on; also that there will be emergencies which will mean that the carers will on occasion be late. Is it so difficult, though, to have backups in place? If a bus breaks down the bus company doesn't say "The bus will be here when it is fixed".

Thankyou for taking the time to read our comments.

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