Disability and Care Support:

Productivity Commission

Draft Report.

Overview and Recommendations.

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Response by

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Context.

Disability is not a lifestyle choice and it is indeed very, very personal. Those of us living with disability (s), experience many different strangers traipsing through the most personal aspects of our lives with their preconceived ideas and perceptions regarding disability. We are usually defined as a disability types rendering others as the experts over and above our own self. Rather than being engaged as a citizen who lives with disability as an aspect of us rather than a summative.

My approach here in this response is from my lived experience, research, and engagement with others living with disability. I will leave other nitty gritty aspects such as the legal's, wages, etc. to others. My perspective is that of a social one.

Thus it is pleasing and a relief to read of this Disability and care Support productivity commission draft where the individuals are the centre point. The possibility for real investment, and social enterprise into those of us with disability to 'get stuck into' life as other Australians is present here. This is the blueprint. It has the possibility to set things right.

The draft report (the long version), pretty much encapsulates and has got a handle on the big picture quite accurately.

I just hope that this is not sabotaged by politicians looking to make political gain at our expense. Or to take support monies from citizens living with disability as a means to fund this.

Strengths – benefits.

For those who qualify this is an excellent and much needed support structure. It is excellent, just excellent with many of the basic bases covered. A proper big picture perspective covering the key operatives such as:

1. The redress in relation to standards on page 41 excellent with consumer based outcomes being the operative.
2. The creation of a data base that will show up the numerous social exclusion barriers. As such the impetus for respective Government policy to create the real opportunity to find redress with actual solutions, rather than tokenistic clap trap and no real inclusion action.
3. Be able to remove conflicting self-serving agendas.
4. Create a common page from which to gather stakeholders to and from which to work from.
5. Lived outcomes as the primary indicator of successful outcomes and program efficacy.
6. Fictional complaints resolution and abuse protections.
7. Potentially just better coordination of disability supports, and service delivery and culture.

Concerns – queries.

It is of tremendous concern that one disability is segregated out for a disproportionate attention due to inadequate matching of qualitative and quantitative research pertaining to other disability types to 'compete' for specific attention.

One can never say that one disability type is more vulnerable or needier when many types are in need of a lot of matching support. It is the respective society around a given individual that will have either a disabling impact or enabling impact. If an individual's disability renders them little or no ability to catch public transport without supported help, but can wipe their own backside, they are effectively house bound.

Two key issue stand out. One pertains to issue surrounding the place of Disability Services – supports role from the State Governments. Will the states be responsible for ongoing support to those presenting with permanent moderate to severe disabilities? Such citizens need support often by way of domestic, home modifications, equipment and assistive technology.

The other pertains to the fact that a vast majority of citizens living with disability present with a number of permanent moderate to severe disabilities with some presenting with health related issues. Of these many are degenerative and need intervention support in order to slow degeneration in order to put of entering into the severe to profound category.

1. Eligibility issue is a major issue. The criterion is too narrowly focussed on the medical model only based on core personal functions, showering, dressing, etc. The criterion needs to be based on core social functions with the medical model aspect being but a part of this.

   The Core Social Function criterion needs to be contextual to citizen's respective community accessibility. The impact of Social Exclusion needs to be factored in as this will impact on a given individual's ability to function. If our society and communities make society more accessible this would lessen the supports needed. As well make participation more likely and accessible.

   For example to follow the American practice of not allowing technology onto the market such as phone unless those who are vision and hearing impaired can access such equipment. Workplaces with volume control phones and T-loop capacity would lessen the need for such support and they would be the standard norm.

   Accessible public buildings, spaces and transport without having to pre-phone ahead to such transport only to be held up and miss the accessible public transport. Disability orientated layer to navigate on top of everything else.

   Universal accessibility as a standard norm on many fronts where citizens could be expected to move around, work, common places, etc., would defray the burden of cost on individuals, and any support scheme.

   The criterion for Core Social Function needs to follow on the following guidelines, factoring those individuals who live independent of parents and family assistance, and who may be single parents – page 21 of the said report is reflective of this:

   a) Personal care – medical model.

   b) Transport – many can walk onto a bus but some disabilities preclude learning how to acquire the skills to catch the bus, e.g., are confused as to how to use the bus, sensory issues, reading bus schedules, preplanning, to name a few.

   c) Education supports as we have a cultural practice in primary and High schools where by funds assigned to special needs students are put into the general budget.

  Students rarely receive direct spending of such funds assigned to them for educational needs thus reducing their opportunities later one. There needs to mandatory reporting pertaining to how such funds are spent, specialists services, equipment, etc.

  d) Actual work capacity being mapped out that addresses not only disability but the accessibility of the community one lives in and access to respective supports.

  e) Domestic support, house, washing, shopping (may not drive), lawns. This is important not just for functioning but for tenancy obligations and requirements.

  f) Supported decision making support, e.g., financial, planning tasks.

  g) Communication.

  h) Work place support- personal supports, equipment, assistive technology, communication, transport.

  i) Social Engagement Capacity.

2. Local assessors need to have an intimate knowledge of respective disabilities and how they play out – impact on respective individuals lives factoring what is or is not in a given individuals life such as accessible community, community supports, and family – informal support. Also the given individuals respective family support, e.g., parenting perhaps a sole parent and maybe a parent with children with disability.

   This is said as the current practice of work assessments is largely done by individuals with no knowledge or expertise of such and override specialists assessments, placing individuals with tasks not deliverable. Such assessments also place individuals in a deficit, as well as look for ways to cut them off from necessary support.

3. The issue pertaining to those who present with a collection of permanent moderate to severe disabilities receiving varying levels of support who under the narrow criterion of the NDIS would not qualify. What will happen to their current type and level of support as for these individuals such support means the difference between functioning and not, as well as slowing down the rate of degenerative changes.

   Page 22 (33 diagram and 45 recommendation 3.2) seems to try to address this, but some individuals are requiring of ongoing domestic support along with equipment, assistive technology, and incontinence aids, in conjunction with what is stated in the first paragraph.

4. There are disability specific barriers to obtaining access to health the key barrier being that disability and health are frequently indefinable to the health services or health issues are deemed part of one’s disability. This impacts on effectively obtaining the necessary assistance by way of services, medication, therapy and equipment, especially if one’s condition is permanent in a timely manner.

5. Musculoskeletal conditions needs to be more clearly defined by naming actual conditions. For example, is scoliosis of the spine in such a category as this can be quite a disabling condition rendering an individual severe restriction?

6. Assessment tool can be objective to the degree that they become a bureaucratic human-less exercise that is prohibitive of being able to make accurate assessments in order to keep the system viable. Staying under budget is already coming through very loud, same as we experience now. Applicants expected to ‘undergo a rigorous’ assessment is going to put them through the mill yet again.

7. Will this assessment be the only one an individual will have to be subjected to? Every scheme has a new round of assessment but is basically getting the same information. Once the assessment is done will this cross all Government and other services and enough information to go over yet again? The repeat, repeat experience.

8. Work capacity assessments need to be in the context of individuals actual disability, actual accessibility to desired career areas, employers willingness or not re-an individual with disability, actual capacity as in disability management strategies and the energy, and mental, physical and emotional time this takes up, along with the emotional drain when dealing with wider societies propensity to exclude one. This alone exacts a high cost with burn out a key issue and emotional depression.

9. Wage component used on disability that cannot be removed, needs to be tax free to make it worth the effort. One has to be able to make a ‘decent’ living given the effort needed if there is little reward.

10. DPS and doing voluntary work is far better for an individuals well being that being forced or coerced into meaningless low paid low skilled work when respective individuals are capable of high function jobs but at a reduced physical energy capacity. For example one may be able to work two or three days per week, but we totally exhausted and needing to balance energy expenditure to retain any capacity.

11. Dealing with discrimination, in the work place and in society makes such venture prohibitive and needs to be redressed very vigorously with penalties. Work place bullying of individuals presenting with disabilities is high with such individuals not having redress by way of immediate redress or access to advocacy. Arrangements currently in place are way under adequate in relation to the need and accessibility to such.

Recommendations.

1. The place of State Government disability support services needs to be clearly clarified here. Ongoing supports for those who present with permanent moderate to severe disability receiving supports should receive ongoing support by the current State Government arrangements. Many of these pertain to permanent neurological spinal skeletal conditions for which early intervention is critical to slow the degenerative process. This is not mentioned in the early intervention group but would need to sit in tier 3c. So what disability support services will be provided by State Governments, for which disability types, for permanent moderate to severe, etc.?

2. Page 46, recommendation 3.4 – the interdepartmental areas of support does need to be very clearly defined with respective protocols for both Federal and State Governments. Else the issue that is current of passing the responsibility and confusoligy will remain the norm practice.

3. Page 47 recommendation requiring the payment of an upfront contribution should be means tested. For individuals who have born the full cost of social exclusion by way of gaining education to properly train talents, and work opportunities to build a career are resource depleted.
4. Disability employment only pertains dominantly to sheltered workshops, or very low skilled and paying work. The cost of disability frequently cancels out any economic gain. The predominant experience of dealing with society's preconceived ideas and discrimination cancels out any social gain. The predominance of disability being the summative and reference point of one rather than the person first with facilitation of disability needs being but an aspect.
5. Citizens living with disability should not be punished by Centrelink or the Government or made to wear the social exclusion practices of society including respective employers. There needs to be a program expecting employers to lift their game and employ individuals with disability in meaningful and with decent pay outcomes.
6. The NDIS will present with yet another confusing set of disability criterion. The UN CRPD should be the standard used for all support schemes. With the use of the UN CRPD one would be better able to define respective supports by this scheme, with the State Governments picking up the rest. Else, individuals will fall through the cracks with no avenue for any assistance.
7. Not to assume that referrals will be acted on by the services individuals are referred to. There needs to be an accountability mechanism to ensure individuals can obtain respective support from the services they are referred to. Else people will fall through the cracks as is the practice now.
8. Contingency plan for when referrals are inappropriate or fail to deliver the assistance needed.
9. Early intervention needs to take on board that ling term assistance may not bring about a progressive 'cure', but will slow down degeneration processes.

Conclusion:

I have included a list from an article I've just put together. I have lived with disabilities all my life. I have to contend with a degenerative congenital Neurological spinal condition, and a severe language disability. I've had to fight my entire life, breaking down barriers trying to 'get into' society to use my talents, skills, etc. This is exhausting enough in itself rendering limitations upon my capacity as I have to employ multiple management strategies to stay upright, balance, decoding language, speech, and the issues pertaining to my spine.

I am yet to receive my due reward that I have work damm hard for.

The biggest waste of my energy pertains to the abuse, bullying from individuals in both the private and public sector and the community at large, preconceived ideas and discrimination that engages you with disability as a summative rather than as a citizen living with such, segregation on the basis of disability, rather than a facilitation with the aim to 'normalising' the presence of such, from deeply entrenched ignorance that is ignorant of such.

Hence the following list. I am in the throws of putting together a very complex master degree that will draw on two disciplines to define Social Apologetics. Personally, I would like to work in the area of community development that creates pathways that normalises the presence of citizens living with disability as a normal aspect on the human spectrum of diversity, without requiring such citizens to be like abelists. Rather, to be able to live in the context and capacity they actually have, as the current practice sees one measured against an abelists capacity rendering one always in a deficit.

It is not the disability that is the suffering and disablement. Rather, it is the systemic aggressive actions of discriminative, intentional, vilifying exclusion and punishment that is the suffering.

The cost of exclusion creates a dept that is exclusively burdened on to citizens living with disability and respective families. The deliberate, systemic social constructs and cultural practices render in-accessible access to society in multiple forms, and is a responsibility of this society as the collective perpetrators of such, and not the victims. This is no more evident than in the education and work place arena, both private and public.

It is time to get real in relation to authentic inclusion and mainstream the facilitation of citizens living with disability. For this to occur there needs to be mandated action, and policy in the following areas to remove the mechanisms of social exclusion (disabelism), to create inclusion (enabelism) – an audit if you like:

1. Mandated quota for businesses to have employees with disability.
2. Mandated financial assistance for employers who have to spend money to facilitate such employees.
3. Mandated meaningful work, as non-meaningful creates a further sense of punishment, disempowerment, and exhausts any value or energy to live that one may have.
4. Mandated tertiary assistance financially and with accessible courses - that is they are tailored to factor in one's respective disability to work to a successful outcome.
5. Mandated reporting of how primary and secondary schools spend money allocated to students with disability needs. If a student has funding attached to them then there has to be mandatory reporting pertaining to what specialists were engaged, equipment, etc., along with the results. This is vital for such a student’s education and future prospects being maximised.
6. Mandatory tax exemption component pertaining to employees where they have to spend money on disability needs, such as travel, equipment, assistive technology that is disability related, service supports, and any other disability related expenses incurred.
7. Mandatory tertiary education opportunity funding to get people with disability into a job market arena that will pay a high wage to maximise given potential as well as take on board the fact the majority of people living with disability have a markedly reduced capacity along with having to encounter a society who basically is discriminative and abusive with only a few pockets where one is treated as a human being. Abelists define you as being the disability as the summative rather than being just an aspect of you.
8. Mandatory work capacity assessors who have an intimate understanding as to respective disabilities, the social capital around respective individuals to map out the actual real life situation before penalising on a blanket one size punishment fits all.
9. Mandatory disability support services for all people living with disability, of moderate, severe and profound and people presenting a number of disabilities.
10. Mandatory equipment needs being immediately met with no waiting lists.
11. Mandatory journey to volunteer work taxi vouchers.
12. Mandatory accessible buildings, environments and public transport.
13. Mandatory assistive technology assistance with no waiting lists.
14. Mandatory use of individuals like myself who think outside the square, have a solid broad spectrum understanding, and are solution based, to be gathered to create a think tank of

those of us whom are being punished to educate the government, businesses and public as to why they get it wrong and create real life affirming solutions.

15. To stop the punishment by providing actual solutions and pathways that work at improving people's life and access to life.
16. Mandatory creation of voluntary programs that actually see people with disabilities mentored at the managerial level positions and work portfolios that document what management strategies employers have used to facilitate employees with disability with accompanying outcomes.
17. Mandatory free access to therapy that is needed to maintain what one has left for preventative intervention.
18. Mandatory free access to learning Auslan with more interpreters and access to such.
19. Mandatory free access to learning Braille and related technology.
20. Mandatory free access to any and all disability assistance.
21. Mandatory responsibility to STOP the propensity of this society to shut people with disabilities out and then punish them and relegate them to the scrap heap of society, with meaningless work penalties forced on them
22. Mandatory commitment to citizens living with disability to not be penalised for what this society has and continues to fails to do and put real investment into us that engages our talents and abilities so that we can grow our own capacity.
23. Mandatory recognition that a continuance of the current penalising of citizens who live with disabilities may choose to end this socially enforced suffering by society by opting for voluntary euthanasia - this option is presented to such citizens as a cost saving mechanism for an economically rationalist driven community.
24. Mandated requirement for all political parties to engage in with citizens living with disabilities and respective families.
25. Mandated requirement for all political parties to prove the prospective efficacy of policies pertaining to citizens living with disability taking on board that such citizens are socially excluded and as such policies have to aggressively redress this for any policy to have any real positive impact.
26. Mandatory working with people living with disability to have tailored solutions rather than use the blanket one diagnosis fits all people regarding respective disabilities.
27. Mandatory ceasing of caparisons with others whom present with the same or similar disabilities. People's achievements are as individual as the presentation of disability (s) in individuals.
28. Mandatory facilitation of engaging citizens who live with disability as the authority and experts on themselves and what works rather than self-appointed self-serving 'experts', who are often removed from the lived experience of disability in a society that basically does not want you and penalises you for your efforts by placing more roadblocks in the way.
29. Mandatory matching support needed to facilitate citizens living with disability into their actual work capacity, rather than place an abelist’s work capacity on citizens living with disability. This sees such citizens always in a deficit.
30. Mandatory stop on pitting citizens who live with disability and families against each other for resources.
31. Mandatory recognition and support for Young Carers.
32. Mandate the function of the Public Service to be the communication conduit between the Public and the Politicians – the respective Government of the day. At the moment they serve their political masters more as the spin doctor machine for the respective Government of the day, and shut the Public voice off from the respective Government of the day. Thus, the media arena is all that is left.
33. Mandate regular reviews of respective antidiscrimination legislation, are they effective?
34. Mandate an Australian Disability Persons Act, that would include access to advocacy as a given, visitors programs, and mandated reporting, etc.

In Closing:

I am trying to slow down further degeneration and have a son on the Autism spectrum and a daughter who is a carer. In fact we three are each other's carers. I hope to and need to keep the domestic support I currently have and would like for my son to receive such, as there is no respite for me. I have to work management strategies for both of us. Parents with disability with children with disability do not see the respite we need due to discrimination against us for having children when we ourselves have disability.

I am getting older and still want my much deserved due career and financial reward that goes with such. A government job in the said field would work a treat – three days a week.

I am like so many very, very exhausted of this society's and politicians exclusion of us, denigrating our efforts, victimising us and then vilifying us for needing supports in the private and public arena. To then marginalises us even further by burdening us with the costs of social exclusion alongside rising living costs. Disability is very expensive for those of us who have no choice.

For citizens who live with disability there does have to be a point to life other than just justifying our humanity.

It is thus concerning that politicians from all persuasions are busy engaging wider society to participate with vilifying, speech, actions and policies intended to punish us, with wider society's silence will be seen by respective politicians as the will of the general public and will be the standard norm. This I believe will impact on the receptivity of the NDIS by Australians.

The NDIS needs to be communicated as an investment into Australians. That this country's greatest resource and asset is its people. That is ALL of its citizens.

Respective solutions need to be flexible in order to fit the context individuals living with disability live in – to work to a successful outcome.

Respective solutions need to work to success not punishment towards individuals who are limited by education access, employers not facilitating beyond meaningless low paid work and void of obtaining any other supports needed.

The NDIS is in the optimal position to bring awareness as to the real picture pertaining to citizens living with disability in the context of social exclusion and its impacts in this country. That is what the actual real barriers are, impacts and to obligate the respective governments, and wider society to get real and include citizens living with disability where such citizens can enjoy rewards for efforts as other Australians do rather than punishment.

Thankyou though to all of you who have worked so hard on this Disability and Care Support productivity commission draft report – everything it entailed.
It is the best encapsulating beginning point we've had and the right beginning point to grow from.
Again thankyou!

Respectfully

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