Submission to the Productivity Commission

My experience with disability

- I have a 24 year old son with a profound intellectual disability; cognitively he is somewhere between 9 – 15 months and needs full supervision and support for every aspect of his life including all personal care and safety.

- I was a member of Disability ACT's Strategic Governance Group for 5 years and the community co-chair of same for the past 2 years. I was heavily involved in developing the new strategic plan. I resigned 22nd April 2010 because I cannot see any way that the department can implement the strategy – the system is both broke and broken.

- I have worked closely with families who have a son or daughter with a disability for the past 2 years as a Family Leader. I see the despair and desperation and I know that the system cannot come anywhere close to assisting the PWD or their family members achieve a good life. I resigned from this position mid-May 2010.

- I set up a microbusiness, JACKmail, around the skills and preferences of my son, Jackson, which buys me 24 hours of support a week. We are in our 4th year of operation and have not missed one mail delivery in all that time. This is quite an achievement given his high level of support needs and profound intellectual disability. Read about it here: www.jacksonwest.org

- My husband Mac committed suicide on 2nd June 2009. He had had bi-polar 2 for 30 years; the stress of having a profoundly disabled son with little support was one of the contributing factors to his frequent relapses.

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

The key focus should be on those PWD who have the highest needs and are at most risk of being forever marginalised in our society; those PWD who are severely to profoundly **intellectually** disabled. To me, there is a hierarchy of disability; some disabilities are more acceptable to the general public than others. I have summarised the hierarchy as:

1. **People who are accepted, welcomed and championed**
   People who have full intellectual capacity, are articulate, have some physical disability and who perform in elite sports or achieve incredible feats of endurance and perseverance. For example the downhill skier with one leg, the blind man who climbs Mt Everest, the quadriplegic professional singer, the beautiful female doctor who was born without lower leg bones, (she gave a TED talk this year). In other words the Michael Miltons of the world.

2. **People who are accepted and welcomed**
   People who have full intellectual capacity, are articulate and have some physical disability and who use a wheel chair. They may hold positions of influence and/or power. They might run companies or organisations.

3. **People who are accepted**
   People who have full intellectual capacity but might use technology or signing to communicate; speech machine, computer, iPad.

4. **People who are reservedly accepted**
   People who have a mild intellectual disability but who can work, converse, sit at a table and feed themselves, catch a bus, form friendships, speak for themselves.

5. **People who are not accepted and might be avoided, shunned, ignored**
   The more intellectually disabled a person is, the more of a pariah they are. From this point on PWD become more marginalised depending on how many of the following added disabilities they have:

   a. Communicate in ways other than speech ("Oh they don't speak and so they don't communicate.")
   b. Have no receptive language
   c. Are doubly incontinent so they need personal care every day and forever
   d. Do not know how to have a reciprocal relationship with a person and cannot form friendships
   e. Drool or dribble
   f. Speak unintelligibly
   g. Wave their arms, legs and heads around in unpredictable and unattractive ways
   h. Make unconventional noises
   i. Need feeding

So I think we need to start with the group at the bottom and work backwards.

If their parents or primary carers have been looking after their disabled adult children until they are 25 or older, then those people must be prioritised first. Start with oldest carers and work backwards.

…how they may be practically and reliably identified.

All you have to do is meet them. People who are as disabled as my son and who need his level of support are easy to identify. There is no way you could mistake the extent of his disability once you meet him.

Or else there are all the usual ways. Have an assessment by:

1. A doctor
2. An occupational therapist
3. A physiotherapist
4. Someone who has the authority to decide the level of a person's disability – this is usually never the primary carers although it almost always should be

A person who has a severe/profound genetic disability should only have to be assessed once. For example my son Jackson has a deletion of chromosome 22. The deleted bit has 2 proteins vital for brain development – he is never going to develop any further than he has already. He needs 24 hour care – he can't need any more than that and so further assessment is pointless.

Which groups are most in need of additional support and help

1. The lower down my hierarchy of disability described above, the greater the need of those PWD and their families.

2. People with severe to profound disability whose primary carers have been caring for them for 25 or more years - note this covers carers in their 70s and 80s whose adult disabled children (I know this should say *adult children who have a disability* but too wordy) are in their 40s and 50s.

3. People who have **no family support.** Families where all the caring is done by the parents and often just one parent who is more often than not the mother. This is intolerable for 2 people – it destroys lives, it destroys families, it destroys marriages, it destroys relationships, people break down irrevocably, people die – like my husband.

4. People who have a child with a severe to profound intellectual disability or a severe to profound physical disability - people whose PWD requires a high level of support. 24 hours a day is obviously high. What else would qualify as high? A sliding scale of assessed need such as those already used by many organisations to determine the level of support which equates to a level of funding. There are enough of them around so you wouldn't need to develop a new one.

5. People with catastrophic acquired brain injury.

6. Families who have 2, 3 or 4 children all with a disability or have a child with a disability and another family member with a chronic else, a mental illness, a brain injury, a terminal illness.

The kinds of services that particularly need to be increased or created

There are many and the need starts from the time of birth. My focus is on the older person with a disability who has aging parents/carers.

The overwhelming need for this group is without doubt **supported accommodation.** In the ACT alone there are hundreds of families who are desperate for supported accommodation.

I started my own quest in June 2002. I started early because I knew it would take me a long time. However, I did not imagine it would take this long – 8 years later **I have been to 67 meetings** and have made countless phone calls and written countless emails and letters. The only time I get a little progress is when I go to the ACT Minister for Disability – there have been 4 different ones since I started.

Supported accommodation for people with a disability needs to be a right and not a privilege; something that a PWD automatically gets once they reach a certain arbitrary age; for example 25 years.

Respite

Creativity needs to be applied here. My own son Jackson was in a shared care arrangement with a foster family for 14 years on a 2 week rotation; that is 2 weeks with us and 2 weeks with his foster family. I never used formal government funded respite houses during those years as the foster family and I provided respite for each other.

This is arrangement I fought for and maintained with great diligence for 14 years and everyone benefitted. Jackson had 2 families to care for him, my family had Jackson-free time in which to do 'normal' things like go to a movie, go camping, go on a bushwalk etc.

The shared care no doubt saved my husband's sanity for 14 years and gave me and my other sons a warm, loving, stress-reduced family life. My other three sons are all doing extremely well in the world – I doubt if this would be so if we had not had the shared care arrangement.

This model is one that could be developed and it would be a great benefit to many families who otherwise could break under the strain of having a child with a disability. I have given presentations on this arrangement and if you would like more details I am very happy to do so.

Of course, other respite choices need to be there for families who need an occasional break. There will always be a place for respite houses but there is a chronic lack of choice for families around respite.

Giving People Power: Portability of funding

The scheme needs to be national so that PWD can take their funding with them when they move across state and territory boundaries. The money needs to be attached to the person (direct funding) and not to an organisation or program. Families at present are bound to stay in the same place as the funding they have received. If that place is the ACT then you can't move anywhere.

Having control over the money is the best way of giving people power. Otherwise we are forever fitting (or not fitting) into programs and services that might not suit us but which are all that is on offer. We are told things like…'you son is too old/young; you are out of area; we have no places left; you don't fit the criteria; you must bring your own funding; we have a waiting list; you are not in the priority group….'

Accountability is always raised here as a problem. "What if people gamble/drink/buy drugs/take holidays/ spend it on cars etc" This is not difficult to police and there are simple ways of people accounting for the funds. In the ACT we have Quality of Life Grants where the money is paid directly to families and they are obliged to account for the monies with receipts. I think this has gone smoothly for the past few years.

The CAAS (Continence Aids Assistance Scheme) is currently in the process of changing the way they provide funds by paying it directly into an individual's bank account so that we can now shop around for the best service and value for money.

If PWD and their families control the money, this is an excellent way of improving service delivery as we have control over who gets our dollar and for what.

Wasteful Paper Burdens

PWD and their families want to tell their story once only and not over and over again. We need something for disability like the Medical eRecord which is being developed for the health industry. **Tell My Story Once** is one of the Strategic Priorities in Disability ACT's new policy document and it is a good one – how they implement it is another matter.

All a person's information needs to be stored electronically. Services or programs or Centrelink or funding bodies or NDIS can access this information and take the pieces relevant for their purpose.

For many of us our situation does not change – except to get more dire. I now look after my profoundly disabled son Jackson on my own – dead husband, no partner, other sons all moved away from Canberra, no family support. But I could add this to my Disability eRecord very quickly and it would updated for all services I use. Perhaps I would automatically move up the NDIS priority list or move from one category of need into a higher one without me going around knocking on doors, asking for help – telling my story over and over again.

Financing the New Scheme

I think a levy similar to the Medicare levy is the only way to go.

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