Sunnyfield Submission to Disability Care and Support Productivity Commission

August 2010

SUNNYFIELD SUBMISSION
Disability Care and Support
Productivity Commission

INDEX

THE KEY QUESTIONS

Disability Care and Support

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Where to start?

A service system for any person with a disability should be driven by a person centred planning process:

> *"a process of learning how a person wants to live and then describing what needs to be done and then helping that person move towards that life"* [i]

- Planning must reflect the aspirations of the person, rather than just addressing their deficiencies.
- Planning must make use of the person's natural support networks (such as family and friends), as well as formal supports (such as disability and health services offered by community organisations).
- Planning must emphasise the support required to achieve the person's goals, rather than limiting goals to what is commonly provided or known.

Therefore people who work in any system which provides support, services or advice to people with a disability, their families or carers must be familiar with a person centred planning process, and where necessary, draw upon people skilled in person centred thinking and its practices.

The Key Questions

1. **Who should be in the new scheme and how could they be practically and reliably identified?**

   Children, young people and adults including those over 65 years with a diagnosed permanent disability who meet the current criteria within ICD-10 standards and which can be categorised as either mild, moderate or severe. The use of a functional needs assessment tool is also required to ensure that an individual's daily functioning is thoroughly understood including the functional, emotional and behavioural needs. The Instrument for the Classification and Assessment of Support Needs (I-CAN) for example, is such a tool.

2. **Which groups are most in need of additional support and help?**

   i. Children, young people, adults and older persons who present with a core activity limitation characterised by the person predominantly requiring personal assistance or supervision with learning, communication, self care, home living, social skills, self direction/choice making, leisure and employment.
   ii. The people identified in (i) with ageing families;
   iii. The people identified in (i) living in dysfunctional families; and
   iv. The people identified in (i) who also have a dual diagnosis.

3. **What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?**

   i. Make specific funds available to people with a disability based upon established criteria and then provide those funds directly to the person or their family to be used for specified service types and support but not specific service providers.
   ii. Create the ability to review each person's support requirements as changes occur throughout their life.

4. **How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?**

   i. People with disabilities or their carers will have the power to make decisions when they are directly funded to support the life they need and choose[ii]. If the funding is in the hands of the person with a disability and/or their family, then the need to appeal may disappear. If an appeal is needed in relation to a specific service then withdrawal from the service is the most powerful message.

   ii. If there needs to be an appeal mechanism then this could be achieved by the establishment of community based panels which include representatives from carers, people with a disability, appropriate diagnosticians and service providers. These panels can provide information directly to an overarching Disability Care and Support Advisory Committee in each state and territory to be chaired by a person with a disability or a carer.

   iii. Ensure that all appeal mechanisms remove all opportunity of fear of retribution.

5. **How should the amount of financial support and service entitlements of people be decided (and by whom)?**

(5.1) A funding formula needs to be based upon a diagnosed permanent disability that meet the current criteria within ICD-10 standards and which can be categorised as either, mild, moderate or severe. This needs to be determined by a national advisory panel consisting of people with a disability, carers, medical practitioners, related disability and health professionals, and a specialist in quality of life assessment.

(5.2) A formula should include the following factors:

- the age of the person;
- the actual daily costs of supporting a person of X age with Y disability (including personal care time, education or work, transport, meals, special resources required), the expected lifespan of this person, and the probability of Y's condition either improving or deteriorating; minus the estimated cost of living for a non-disabled person of the same age, and
- the assessed functional[iii], [iv], social, emotional and behavioural needs of an individual.

(5.3) Consideration should be given to weighting the formula for a:

- person who has multiple/complex disabilities which isn't articulated by the ICD-10;
- person who lives in a regional or remote location;
- person who requires long term supported accommodation;
- person who does not have family support or who has been abandoned;
- a person whose family are unable to provide appropriate support; and
- person with little or no effective communication.

(5.4) A funding formula needs to incorporate a national award increase for front line staff for the sector to be able to attract highly desirable and competent staff.

6. **What kinds of services particularly need to be increased or created?**

Generally, services and supports should target key transition points in a person's life such as at birth, entering school, leaving school, going to work, retirement and ageing;

- Person Centred education and training[v];
- Counselling and family support;
- Educational support for children with a disability in regular and special school settings;
- Community based health, medical assessment and support;
- Short to medium term respite support;
- Flexible accommodation options including long term supported accommodation;
- Social support services (recreation and leisure) to enable people to be more included in their local community;
- Employment;
- Retirement options for people with a disability who are ageing; and
- Support for people to age in their home.

7. **How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?**

- Provide more facilitation support for people with a disability and their families;
- All services providers and their facilities should be accredited, registered and reviewed every three-five years;
- Service and support information for people with a disability should be available through on-line, telephone and shop front options;
- Service and support information should be accessed through a local community network whose task is to provide both information and case management support to individuals or families;
- Reduce the duplication of documentation to be completed each time a family or person with a disability changes services or supports;
- Service provision should be driven by the needs of individuals with a disability rather than individuals having to accept what's on offer. Self-directed and self-managed programs will require better funding as there will be a need for more casual and part-time staff to work flexibly across different people, locations and times;
- The local community network should maintain a database of all eligible service providers and put people in contact with appropriate service providers or act as a broker to people or their families; and
- Require current Non-Government Organisation's (NGO's) providing similar services to establish partnerships, pool resources and reduce the terrible duplication of services especially back office infrastructure.

8. **Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?**

Generally, interventions need to target key transition points in a person's life such as at birth, entering school, leaving school, going to work, retirement and death;

- Improving a person's quality of life can begin at any time but needs to begin as early as possible.[vi], [vii]
- Intervening early with families would have a significant positive impact on the on-going health and welfare of families;
- "Early" intervention can occur at different times in a person's life not just 0 – 4 years. The earlier a person can receive a service that is needed in that person's life the better the quality of life will be achieved. For example, a young person leaving school should be part of a transition process that commences 12-18 months prior to the person leaving.[viii]
- Just because a person didn't experience or benefit from an intervention when he or she was a child doesn't mean that they won't benefit as an adult. For example, there are many thousands of adults with a severe communication impairment that would significantly benefit from an appropriate communication strategy and training[ix], [x]whose quality of life is extremely poor because they receive no support and assistance in specialised communication support.[xi],[xii],[xiii],[xiv],[xv],[xvi],[xvii],[xviii]
- It must be acknowledge that people with a disability are adults for longer than they are children, therefore the type and level of service required by a young child will likely be needed but in a different way as a person ages.

- Quality of Life assessments[xix],[xx] should be conducted for every individual every 5 – 10 years in a person’s life.
- Create a national census and database to capture all people with a disability, their age, type of disability, other needs and location.

9. How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

- Provide funds directly to the person that can be used to support an employment option or to be more included in the wider community;

> *“All people deserve the opportunity to develop independent skills, to reach out and to explore their individual potential. This program opens the door to explore and build upon personal strengths. It is not a panacea to the problems within the disability sector, but it is a way of determining what works for the individual and how personal capacity can be explored, created and embraced.*
>
> *In time I hope that my daughter’s choices really become her choices, currently we are still making the decisions for her.” I want my daughter’s personal strengths to become her defining element rather than her disabilities. This will take time because of her unstable mental illness, although I do now finally see hope on the horizon, something we did not have until we began this program.”* (Parent whose daughter receives an individualized package managed by Sunnyfield)

- Make all buildings accessible;
- Assist individuals with disability to better connect to their local communities;
- Educate the broader community about valuing and supporting people with disability;
- Provide employers with tax incentives, reduce red tape to employ people with a disability;
- Mandate that all public transport is accessible for all people all of the time by 2020;
- Provide incentives for service providers to provide more direct services and support in the wider community;
- Any new scheme must formally acknowledge the UN Convention on the Rights of Persons with Disabilities to guide the actions, rights and entitlements of all people to appropriate services, care and support;
- Mandate that all government departments and local councils must support Australian Disability Enterprises (ADE’s) through preferred purchasing initiatives; and
- Refer to the United Kingdom’s new strategic plan for a whole of Government response to how people with learning disabilities are entitled to the same aspirations and life chances as other people.[xxi]

10. How can a new system ensure that any good aspects of current approaches are preserved?

- Ask carers and people with a disability about what’s working for them and what’s not working. Some things may be idiosyncratic but most things will be general to the wider population;
- Establish robust and realistic age-appropriate outcome measures[xxii], [xxiii];[xxiv] [xxv],[xxvi],[xxvii]
- Look at current measures of effective approaches and where they are being used;
- Use the research literature to inform about best-practice in a particular area;
- Look for services that are achieving people’s dreams and aspirations; and

- Look for programs who are achieving high quality of life measures.

11. What should be done in rural and remote areas where it is harder to get services?

- Provide a weighting to all disability funding in regional or remote areas;
- Provide tax and regional location incentives to encourage people to remain in their local area and encourage prospective employers and employees to relocate to regional and remote areas;
- Consider regional redevelopment funding to local regional councils to support the development of disability services in the local area;
- Encourage people on 457 visas to support disability work in regional areas;
- Require doctors, nurses, and allied health professionals to undertake mandatory locums and practicum in regional and remote areas; and
- Actively establish disability services in specific regional and remote areas to retain and attract employees.

12. How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

- Establish a robust accredited and registered service provider system which is reviewed every 3 -5 years then place trust in this;
- Establish a benchmarking system for services and agencies;
- Establish interagency protocols to end the duplication of paperwork;
- Required current NGO's providing similar services to establish partnerships, pool resources and reduce the duplication of services especially back office infrastructure;
- Assessments should be accessed through a person's local community network whose task is to provide both information and case management support to individuals or families; and
- Invest in a disability electronic database such as the current medical records system.

13. How should a new scheme be financed?

- Firstly, any funding initiative must be in addition to what is currently being provided;
- The easiest way is through the proposed NDIS concept – an additional levy on tax payers to cover the costs of appropriate care and support;
- A better way is to reconstruct the current system of funding, create one national policy and funding (not services) agency for all people with a disability (young children to aged) who directly fund individuals and families; then top this up with a significant increase in funds obtained through:
    - an NDIS scheme;
    - an increase in the GST where the increase is quarantined for a disability care and support program;
    - allocating more of the existing taxation receipts to the disability sector and reducing expenditure in less important areas;
    - creating greater opportunity for families of people who have disabilities to generate more funding through tax incentives;
    - contributions from families for specific service types;
    - a "super tax" for large corporate and quarantine this tax for the disability sector; and

- a government bond which is issued by the federal government as a fixed and "no-risk" investment vehicle. This could be a very attractive investment vehicle for short or long term investors

Note

Is the Commission aware that a parent of a child with a disability is not able to make a donation to an NGO that support's their child and claim this as a tax deduction? These types of barriers and disincentives have to be removed in any new scheme.

There are three and possibly more options to be considered in establishing a bond for this purpose:

(13.1) By investing in a special government <u>Care and Support</u> bond, parents of children with a disability would be lending money to a government and in return, receive a fixed and secure rate of interest until a specific date when the bonds mature, then receive the face value of the bonds back. For this to be attractive to the community of parents/carers, it would need to have the added incentives of (1) the interest earned being tax free as well as (2) the parents receiving a reduced personal tax during their working life if the bond is applied solely to their child's future care and support. This will require a legal and binding instrument applied to the bond holder for basic care and support provisions which include, housing, therapy, personal care and medical support.

(13.2) The Care and Support bond could also be open to the broader community in much the same way that people currently sponsor children in overseas countries. This is a more philanthropic purpose that would encourage citizens to invest in the bond to be able to achieve the dreams and aspirations of those with a disability. In order for this to be attractive, it too would need to attract a positive taxation treatment for the donor or sponsor. In this case, the bond holder would not know the identity of any one person but know that the funds would be part of the pool that supports people with a disability.

(13.3) The "Care and Support" bond could also be open to corporations as part of their "community giving" campaigns and through ATO approved salary sacrifice arrangements, make a dollar for dollar contribution to the bonds to match the contributions made by their employees.

14. How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

- Enact specific Government legislation which commits all current and future governments to deliver a "basic" care and support funding package to each person based upon the developed funding formula described in point 5.
- Develop an economic model based on the known and the expected future disability sector and the drivers of disability growth at the national level, and quantify the effects of policy and other key impacts on the cost of supporting people with a disability.

15. What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?

- Funding is in addition to what is currently provided;
- One national policy and funding agency focused only on people who are disabled;
- Funding is to be directed to people with a disability and their family who will decide how best to use these funds;

- A new Disability Care and Support Program should be quarantined against complex bureaucratic on-costs;
- A new Disability Care and Support Program is protected from successive changes in Government through appropriate legislation;
- Each state has a Disability Care and Support Program Advisory Panel with the responsibility to accredit and register disability service providers, hear appeals and support local community Disability Care and Support Network Committees; and
- Refer to the United Kingdom's new strategic plan on how people with learning disabilities are entitled to the same aspirations and life chances as other people and the impact of person centred planning in the UK[xxviii]

16. How long would be needed to start a new scheme, and what should happen in the interim?

- Unless a new scheme can start immediately or within the foreseeable future, the sector will continue along as it is. There is an imperative for the Productivity Commission to be "brave" and to make the strongest recommendation to the Government that there is no time to spare nor to prevaricate on this issue.
- In the interim period, the Federal Government needs to provide specific and significant top-up funding targeted to those individuals who are most at-risk due to poor health, loss of family, remoteness including those requiring supported accommodation and those needing to leave large residential care.

CONCLUSION

The question all Australians should ask themselves is: ‘Do you believe that you deserve the opportunity to have a chance at getting the best this world has to offer you?’

At Sunnyfield we believe we all do.

We passionately believe that people with disabilities should also have the same opportunity – no more – no less – just the same opportunity as everyone else.

Size of the task

The Productivity Commission’s Issues Paper eloquently proves that this is currently not the case.

As we read the Issues Paper we went through a cycle of strong emotions:

- Firstly we were impressed – in one paper the Commission managed to summarise all of the issues, problems and the pertinent questions we need to face up to.
- Then we were frustrated – frustrated by the sheer size of the task.
  Is it all just too hard?
  Do we just struggle on, doing the best we can?
- But then we felt ashamed – how can this happen in a modern and prosperous country like Australia? We should all be ashamed that a significant number of Australians are not given the same opportunity as everyone else. We are letting down the most vulnerable in our society.
- Lastly we were inspired – we should not lose sight of what the end game is.
  We shouldn’t get stuck in the minutiae.
  Remember people with disabilities deserve the best.

We need to devise a strategy to change the world, so people with disabilities can have the best life possible.

Why should we do this? – because it is the right thing to do – so we need to be brave – we need to stay focused. We need to dig in and achieve what we know is morally right for people with disabilities.

We need to stay focused

- The end game is the people with disabilities. We need to ensure they live their lives to the fullest.

- As we said in the opening to our submission, this will be achieved if we follow a person centred approach. The quote in our submission about person centred says it's 'a process of learning how a person wants to live and then describing what needs to be done and then helping that person move towards that life'.

- There is a lot of talk about new systems and initiatives like the National Disability Insurance Scheme and Individualised Funding. These are important, but they are not the end game – they are only a 'means to an end'. Lets not forget that.

So what do we need to do?

- We need to substantially increase the funding to people with a disability. This just has to happen. An insurance levy like the National Disability Insurance Scheme seems to be the favoured solution.

  Consideration should be given to other additional means as well:

  - Allocate more of the current budget to disability. For example, we should spend more on people with a disability than we do on trees or submarines or whales or opera or advertising etc.
  - Improve tax incentives for family contributions. Maybe a family with a child with a severe disability shouldn't pay any taxes?

- We need to provide services using a person centred approach which delivers what the people want and need. We have to move away from simply focusing on care for the individual. Care is vitally important but all individuals have dreams and aspirations – we need to deliver on those as well.

- For person centred to work we need to shift the power away from the government(s) and service providers, to the people with disabilities and their families.

  The best way to do this is to give the funding directly to them and they decide:

  - What they spend the money on.
  - When they spend the money.
  - Where they spend the money.

  Introduce flexibility into the funding arrangements. Some people may wish to remain in the current system (blocked funding), some may wish to organise the provision of their services themselves (along with their families) and most will want to be somewhere between these two extremes – it is their choice.

- The service providers will have to be more efficient, effective, innovative and customer focused. If they are not, they won't survive. This will bring the powers of demand and supply into the Disability Sector.

  The result will be that people with disabilities will get what they want, from who they want, when they want it.

  A word of caution. You should only introduce individual funding once the level of funding has been increased for the sector. Otherwise the current funding will go to fewer people than it currently does.

- We need to improve the inclusion of people with disabilities into our community. Until they are valued (and actually feel valued) by society, we won't have full inclusion.

  Imagine you went through a person centred session with your family and friends:

  - We looked at what is working for you.
  - We looked at what is not working for you.
  - We listed all of your dreams and aspirations.
  - We developed an amazing plan.

  But then someone says – here is your plan but because of ignorance and prejudice you can't include society/community in your life – what sort of plan would that be?

  When we have full inclusion, then people with disabilities can have full lives if they want to.

  A start for this would be including person centred approaches into Australian legislation, just like the UK. Why don't we include the UN Convention on the Rights of Persons with Disabilities into our legislation? Imagine people with disabilities having a legal right to inclusion in our society, and care provision.

One thing is for sure – what we currently have is not working – the status quo is not an option. It is a whole new world and we need a whole new model to achieve what we want.

F Francis

Frank Francis
CEO
August 2010

P. McKenzie

Patricia McKenzie
Chair, Sunnyfield Board
August 2010

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