Introduction

A truly great civilization does not look upon those people with a disability as an impost, but as a precious gift that can foster the very best in humanity.

In Australia today there are many people that have been born with a disability. They did not ask to be born nor did they ask to be born with a disability. In truth it is a numbers game. As parents of a 19 year old son with severe Autism We are somewhat appalled that if you have a disability you are a second class citizen in one of the wealthiest countries in the world. In this response we want to focus on the disability of Autism Spectrum Disorder.

Question 1.

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

I think that the focus for the new disability scheme should cover disability present at birth, or an acquired health condition, but not due to the natural process of ageing. Any disability that is acquired through an accident should only be covered if other forms of compensation are not available.

One group in particular that I would like to see included are those formally diagnosed with Autism Spectrum Disorder. Diagnoses of Autism Spectrum Disorder are both practical and reliable processes for identifying people who must be included in new and improved services for people with a disability.

Question 2

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

In 2007 Synergies Economic Consulting did a report into the economic costs of Autism Spectrum Disorder (ASD) in Australia. The report concluded that the economic cost was between $4.5 billion and $7.2 billion per annum. When this is combined with new data that suggests that the prevalence rate for Autism is doubling every 5 years, I believe that this is one group that needs additional support, both directly in services and indirectly in research funding to find out why the condition is doubling every five years. This is not to say that there are not many other disability groups that also need additional support and help.

Question 3

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

For autism spectrum disorders:

1. 20 hours per week of intensive, ASD-specific early intervention therapy for every child that presents with Autism.

Based on the above mentioned report, this one service could save the Australian economy between $2.25 billion and $3.6 billion per annum. As for the emotional economy, I can not put a price on it. For every one child that is helped we grain two productive community members – the child and a carer.

This therapy as been scientifically proven. At least 50% of children with autism that have participated in at least 20 hours per week of intensive, ASD-specific early intervention therapy for several years are able to become productive community members and the remaining children have shown improvements with their condition.

http://www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html#autism

The Australian Commonwealth Government itself advises parents that children with autism spectrum disorders need at least 20 hours per week for several years of intensive, ASD-specific early intervention therapy, but to date have failed to fully support this option.

http://www.health.gov.au/internet/main/publishing.nsf/Content/D9F44B55D7698467CA257280007A98BD/$File/autbres.pdf

2. Whole of Life planning for people with a disabilities

There appears to be a lack of ability in governments to put in place long term planning for the needs of people with disabilities.

Given our understanding of disabilities and resources needed for that person for the whole of their life government organizations should be able plan ahead to ensure that the resources needed are available for both the disabled person and their carer.

3. Respite services across the board like after school care, in-home respite, vacation care and flexible respite options.

   For many families with a child with a disability the financial, emotional and time for caring constraints imposed by the child's disability has meant a significantly decreased level of work and community engagement for carers. In these situations there is a loss of productivity to society. The ability to have respite eases the burden for carers. I would strongly advocate for increased flexible respite options as not every family/disability situation is the same.

4. Appropriate accommodation and living support

There is just not enough places for permanent accommodation or living support for any disability groups. I believe we have a real existing problem in this area which will only increase with our aging population. Where are all the severely disabled people, and in this category I class those who cannot actively look after their own daily needs, going to live when their carers die? For my own family this is of great concern.

Question 4

Ways of achieving early intervention

For Autism Spectrum Disorders essential early intervention could be provided, at little extra cost, by:

- Having professionals who fully understand intensive ASD-specific early intervention. These professionals would design and supervise therapies for individual children.
- Having therapy technicians who work directly with the child. Therapy technicians would be supervised by professionals. "Therapy technician" could be a qualification in its own right and could form part of a university or TAFE course. For example the level of Therapy Technician could be attained after one year of study in a three year university course. In some cases the qualification could be an exit strategy or conversely a way to get students interested in further study. Qualified students would have the opportunity to earn an income. The resultant work experience could be used as a further learning tool or a possible method of gaining "experience hours".

Question 5

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

- If we can ensure that when a child has a diagnosis of autism they will have access to intensive ASD-specific early intervention and behaviour support program, we will greatly increased the odds that we will have two productive community members - the child and their carer.
- Having available after school care, in home respite, vacation care and flexible respite option that span working hours. Our son only has funding to cover from 9:30am till 4:00pm for 4 days a week. We are very fortunate because of flexible start and finish times I have full time employment and my wife works part time. For many people caring for a disable person this would not be possible.

Question 6

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

I think that one way would be to have a funding package for each client which could be taken to disability service providers for provision of programs such as day programs and flexible respite services.

A mandated flexible appeal mechanism that service providers and clients/carers must adhere to. I have mentioned flexible as service provision and needs vary with each client and the variety of services that are provided by service providers. I am not sure how to make this process workable without being too bureaucratic. I think the basic principle would be that both the client/carer and the service providers have the right to put forward a issue/complaint that would be fairly listened to and acted upon, with some sort of a lower level appeal process to solve outstanding issues. This could run like the existing Guardianship Board, where the board travels around districts making decisions. Formal but informal as well. There are no courts, lawyers or anything like that. It is quite possible this process is already in practice in some way, e.g. through best practice principles within the disability services sector. I could not fault my son’s service providers on this as I feel confident I could approach them if an issue should arise. I guess this suggestion is a safety net.

Question 7

How to improve service delivery — including coordination, costs, timeliness and innovation

1. Coordinated disability service providers

Currently in NSW our son has a funding package for a day program from the NSW state government through which we have been able to choose an appropriate disability service provider (House with no Steps).

We have access to respite with a NSW Government department and also the commonwealth respite services. I would describe the NSW service as bureaucratic at best. As for the commonwealth service, we have accessed it twice through the NSW government department but I am unsure what we are entitled to or how to access the service. Services are very piecemeal. One service does this, another that.

I think it would more efficient to have disability service providers provide a range of services to a client - respite services, day program options and possibly long term accommodation.

This would have a number of benefits to both to the client and their family.

- Respite could be part of long term coordinated plan to transition a client into a group home setting
- Organisational knowledge of clients in their care
- Families have peace of mind knowing that the service provider understands the needs of their family member
- Flexible respite options
- Reduction in paper work

2. Register of services

At the very least there should be a register of services that are available within a particular geographical area. This could be a bit of a hot potato if some areas had less services than others so maybe the lists could be region wide, e.g. Illawarra. On the other hand if might also show where gaps in services are. For families/carers this would be very useful as at the moment it is very confusing to know what is actually available, from what service, when, for how long, costs, who to contact, entitlements, etc. The register would need to cover government services (State and Commonwealth), non government agencies and commercial services.

Question 8

The factors that affect how much support people get and who decides this

As a productivity commissioner would you be happy to be permanently on call 24 X 7 365 days a year for the rest of your life no weekends, no annual holidays, no sick leave, no workers compensation insurance, no long service leave and no super or retirement for $46.00 a day?

First we must recognise that carers are not some form of slave labour and they are entitled to all the things found in the most basic of awards.

Equally it must be recognised that the person in care is entitled to a level of care that ensures there physical, mental and spiritual needs are meet and that they are not simply left in a corner to live out their lives.

So how do we judge how much support a person should get?

I would like to propose that we judge that level of support on how much it would cost to support that disabled individual in an accredited organisation on a full time basis.

Question 9

How to ensure that any good aspects of current approaches are preserved

Industry awards and recognition of best practise. We do this sort of thing in the Education and commercial sectors. Why not in the Disability sector? Recognition of best practice is a form of promotion for the main funding body – the government. It also lifts the game for the service providers who aim to achieve the award/recognition and can then use this recognition to promote their own services. Recognition could be linked to additional funding on the understanding that this is extra funding, not a basis for the provision of funds to meet normal requirements which would be already covered within the normal service standards required by the industry and government.

Question 10

What to do in rural and remote areas where it is harder to get services

With the new national broadband network you could have trained professionals remotely supervising Therapy Technicians (see answer to question 4).

The disability sector is a hands on business needing staff to work with clients. Being from a semi rural area I know it is hard to get the services. For example we do not get the same availability of services as a metropolitan area and this would be worse for more rural and remote areas. In a lot of cases the client is required to move far away from existing carers to access services. This has real disadvantages to the client who does not have the back up support, commitment and advocacy from family members. It also means staff working with the client have lost a valuable source of knowledge and expertise about the client. I can only say that the government needs to put more funds put into the system, particularly in rural areas. With so many causes needing extra funding we can't always get all the funding we want or think we deserve but it is possible to rethink the way we do things. With the announcement of extra funding, the government could call a forum of interested parties who could work on realistic options to provide better services for disabled clients in rural and remote areas and then carry out the reforms in a timely manner. This would need to be on a regional basis so the relevancy of rural situations is not lost.

Question 11

Reducing unfairness, so that people with similar levels of need get similar support

By ensuring that every person undergoes a complete and comprehensive assessment and those people doing the assessment fully understand the nature of the disability being assessed. Assessments should be carried out in a number of different situations and locations. For example a quick ½ hour visit to a client's home or a professionals office is not always sufficient to fully judge a persons capabilities. It may be that the client is having a great day, or that they are in a "safe" situation/environment – not showing the full range of the limitations of their disability. For example a client might visit a professionals office with their carer and feel safe and calm while the carer is with them. This does not take into account the clients total change of behaviour, panic and inability to look after themselves/respond effectively to their environment, when the carer is not available. This is limiting to the client and the carer.

Regular revision and the streamlining of application processes for both clients and funding agencies. This would include guidelines of disability levels for the use of funding agencies. This will help with bureaucracy. An example of effective streamlining that our family experienced was the changing of funding forms to recognise that if a child is diagnosed with a certain disability they will have certain needs and therefore extensive yearly filling out of forms with the same unchanging information was no longer necessary.

Question 12

Getting rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and reducing duplication in the system

As a family we have experienced this quite lot, especially in our son’s earlier years. There are no clear pathways for diagnosis, treatment and future care. There is a need for a national step by step plan (or guidelines) for clients/carers, medical practitioners, associated professionals.

A client gets a diagnosis from … (this sort of professional person/s),
then a client sees ……,
then a client sees ……. for funding,
for …. sees…..
And takes with them ….. documents/diagnosis papers/supporting documents.

Question 13

How to finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future

The new scheme should be funded through a Medicare style of levy.

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