

Response for the Productivity Commission investigating feasibility of a National Disability Insurance Scheme

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Australia always trying to instil 'Best Practice'

Improving the system

The key question for the Commission is not how bad the current system is — nearly everyone thinks it needs to be overhauled. What we want to know is how to build a good system. We would like to hear your ideas about the features of a new long-term disability care and support scheme, based on your own experiences as a person with a disability, or as a service provider, carer, family member, friend, employer or workmate of a person with a disability. As shown in the chart below, there are many aspects to a scheme's design, and we have to make informed judgments about all of them.

Who should be eligible?

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

- All individuals born with disabilities, intellectual, physical, medical
- All individuals who acquire disabilities intellectual, physical, medical, accidentally acquired, mental health
- Identified in hospitals, through medical supports, educational facilities, professionals, DSM, source best practice from other countries
- In Ontario, Canada new local within shopping malls intake/information shops are being set up to support individuals to easy access to information and making themselves known within the system for supports (ground level response)

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

- There is such crisis within the 'system' that all areas are in severe need
- Early intervention for children with disabilities autism, downs syndrome, hearing impaired/deaf and blind etc
- Multi-complex with intellectual, physical and medical needs,
- Young individuals living in nursing homes,
- Ageing parents supporting ageing children with disabilities at home
- Ageing individuals living in systemic environments SSA's and individualised home environments
- **Note: individuals who acquire a disability covered by TAC are already supported with required assistance which provides support for adaptive vehicles, home modifications, wheelchairs etc**

WE ARE JUST ASKING FOR THE SAME BENEFITS FOR ALL INDIVIDUALS WITH DISABILITIES

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

- Use business systems like data bases, tracking, categorising some similarities with some disabilities for matching best outcomes with best practices
- Have national information tracked into a main system that is transparent so the all jurisdictions and organisations can access to see for benchmarking
- Individualised Whole of Life Person Centred Planning from time of 'disability' including all informal support networks as well **research UK and Canadian system as deemed 'Best Practice'**

It is my experience that wealthier families receive larger funding support than socially disadvantaged. It is also my experience that families in rural communities are more disadvantaged and socially isolated. Resources of supports are limited and information dissemination is even worse as to what is needed and what is on offer.

- Require transparent and easy access to information for all can access many forms of communication via media, internet, social program employees, information continuously done via schools, preschools, medical practitioners, hospitals, etc 'Knowledge is Power'
- NDIS will support increased opportunities for new business development, better supports and suppliers of equipment, increased training for potential employees, as more innovative supports are put in place, marketing of outcomes will bring information to the greater public then others will benchmark

Who gets the power?

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)?

- Instil policy and practices around self-directed funding and individualised funding **See: UK and Canada for policy direction UK has mandated that April 2011 all new individuals entering the system will only receive individualised funding, these systems also are leaders in early intervention and better supports in educational venues for students and families**
- Instill Whole of Life authentic person centred/directed planning that evolves continuously **See resources www.supportplanning.org, www.celebratingfamilies.co.uk, www.learningcommunity.us, www.helensandersonassociates.co.uk, www.parent2parentqld.org.au, www.kendrickconsulting.org**
- Don't have a bureaucratic system keep the system close to the person/family
- Could have a appeal process with a committee that has volunteer members, people with disabilities and families including professional on it – rotate this committee so that members are only allowed to stay on for limited duration

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

- A whole of life model of support required, with person centred planning using all life domains an individualised budget developed around short and long term goals within these domains
- Keep decisions and planning close to the individual with local service providers which can be accountable to 'local' funding body resource contacts
- A committee could be an overseer of entitlements using best practice models already identified as benchmarking, localities of support services should be identified within a 'data system' Again individuals on such a local committee should include volunteer members, people with disabilities, families, professionals not full of 'bureaucrats'

What services are needed and how should they be delivered?

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

- Early intervention, integration support into community services eg: daycare centres
- Continuous training for professionals and front line staff that evolves and incorporates best practice models, developmental empowering support, how to use special equipment and inclusive practices for all individuals
- Aids and equipment services, importers of innovative and efficient equipment that supports inclusion Reference: surfing equipment used to support individuals with complex needs to surf in Queensland made in Canada
- Personal support staff for individualised support in homes
- Communication devices equipment, computer programs for people with disabilities, access to more TTY in community, Relay communication systems readily available in public
- Community venues accessible use Active Learning Model Projects to facilitate physical changes in community
- Transport systems accessible SEE Toronto Transit Commission developed a disability service system as a new service arm all localities should be supported to model

- Expand models of respite to meet present and future need until system becomes individualised
- Supported employment and individuals with disabilities being able to have fully funded adaptive equipment transfer with them that supports them to modify work environment for positive outcomes/success in jobs – **Note part of employment barriers is that employers hesitant to supply adaptive equipment OR modify work environment required for successful positive inclusive working experience**
- **My daughter is profoundly hearing impaired and has had difficulty with usage of reliable equipment, it is always in for repairs, she doesn't have support of interpreters in secondary school, she hasn't had ability to choose support that she needs but had to have her funding used to purchase support of a teacher assistant which couldn't support her deficits in learning curriculum RECENTLY ADVOCACY HAS CHANGED THAT I WAS SUCCESSFUL IN GETTING HER \$1,400.00 PER TERM USED FOR SERVICES THAT TRADITIONALLY NEVER HAS BEEN DONE BEFORE THANKS TO GETTING MACLEOD COLLEGE ON THE SAME PAGE FOR ASHLEY**
- Innovative homes and accommodation, support to develop 'circles of support' models, there is various innovative service models in other countries **See resources**
www.cacl.ca www.inclusion.com www.elpnet.net www.icof-life.ca
www.microboard.org www.circleofinclusion.org www.nightlife.org.au www.jaynolan.org
www.microboard.org.au www.circlesnetwork.org.uk www.mamre.org.au
www.in-control.org.uk www.in-control.org.au www.juliafarr.org.au www.c-q-l.org
www.homecommunity.com.au www.dsto.com www.paradigm-uk.org www.homeshare.org
www.oclinc.org www.openminds.org.au www.inclusive-solutions.com

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

- Streamline the system do not add layers on layers of systems – bureaucracy kills
- Start at the coalface with the person with a disability to create coordination of supports and costings there
- Innovation comes from teams of people thinking in collective and brainstorming processes and the person with a disability and/or natural support networks know more of what is needed especially if they are knowledgeable eg: communication devices presently aren't encouraged in the greater community so many don't have these supports to use
- With a person directed service system timeliness decreases as non bureaucratic systems encourage efficiency and transparency
- **See reference: Shaping the Future Together: A strategic planning tool for services supporting people with learning disabilities - www.valuingpeople.gov.uk**

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

- YES, Educate public, professionals, medical practitioners, about human rights, disability inclusion and support, help create 'community models'
- Start Whole of Life authentic Person Centred Planning that continuously evolves with the individual through all life transitions
- Support building informal supports with carers, extended family and building community informal supports to exchange traditional 'paid supports' this means greater training for community members and community employees within community venues eg: recreational facility to have staff trained in manual handling practices to support a person with a disability to be hoisted into a pool
- Early intervention especially in Autism has well documented positive outcomes to where over a life time less support may be required in some documented cases diagnosis has been removed with certain models of early intervention **See research Applied Behaviour Analysis, Positive Behaviour Support, Dr Loovas**

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

- If supports are provided that support needs to person with disability then focus of support will encourage inclusive participation in community
- Adaptive equipment will be accessible to support inclusiveness in community and work
- Carers will be able to relinquish large bulk of caring role therefore gaining a 'life' for themselves to enjoy community participation and work
- Person with disability can look forward to developing a 'HOME' of their own instead of having to live with parents/family members

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

- Hopefully this inquiry will be looking at forward policies that are in place within the states and jurisdictions and support a unified policy direction overall the country so change is driven from the top leadership and implemented and driven in the coal face of the system
- Some of the states are further ahead in implementing individualised packages and self-directed packages of support, while they presently are not supporting whole of life needs or planning incorporating the domains of life appropriately this will change with 'Accreditation'
- Quality Frameworks and Accreditation is a framework that is being implemented in Victoria as mandatory this needs to be strongly enforced in all states
- **Personally I have been trained to use 20 Domains of Life in Planning but in Victoria the Quality Framework recognises 17 Life Areas Maybe a high grade unified Quality framework should be developed across all states to develop a unified system**

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

- Encourage service providers to develop rural branches of their organisations
- Provide incentives for local councils to encourage business development to potential developers
- Encourage incentives for local residents to become service providers
- **I personally would develop multiple services in rural areas if the NDIS was in place to help individuals pay for the services they need. I would create a franchise model of an early intervention service for children with Autism**
- Poll schools etc for individuals that are not visible in 'system' and gain big picture of needs then with planning support individual as best as possible import supports required eg: adaptive equipment etc
- **It is my experience that smaller rural communities are more accepting of the neighbours helping neighbours and the 'community spirit' Inclusion Best Practice can actually be found in some small rural communities with development of natural supports and work opportunities**

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

- Planning and supports done in the coalface with the individual will be first and only port of call no duplication of assessments with various supports services
- Develop multi-disciplinary teams from the onset to include all specialist eg: speech, occupational support, developmental support, life skills etc
- These teams will transcend as the individual moves through transitional life phases and can be more responsive at this level in unforeseen crisis situations eg: medical complications
- One port of call into the system, planning, assessments, choosing what's required now what's future planning (short vs long term goals), creating a potential budget, get approved, choose support services from agencies and live
- **Experience in Victoria when 'support planning came into effect due to the Disability Act' every service provider decided to make a individual support plan for person with disability. Some individuals have anywhere from 2-6 plans instead of creating a team and developing 'One Person One Plan' which is best practice in other countries. Unfortunately, in Victoria**

the Government is also a service provider and in my view hasn't been a good model of leadership in creating best practice or adopting same from other models even though they resources these models within their policies and manuals.

Funding

How should a new scheme be financed?

- The same way Medicare is financed would be fine
- How is TAC financed?
- Maybe employers could be required to support a dollar a day into the fund for each staff member out of profits
- Non-profits to be exempt from this

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?

- Proactive planning needs to be incorporated seeking knowledge of future needs this was quite prominently mentioned in the recent report **Reference: Inquiry into Supported Accommodation for Victorians with a Disability and / or Mental Health and Government Response to recommendations.** www.parliament.vic.gov.au/fcdc
- **Shaping the Future Together: A strategic planning tool for services supporting people with learning disabilities** - www.valuingpeople.gov.uk can also provide some support in future direction
- **Look to countries of best practice and not re-invent the wheel but learn from their journey and don't follow their mistakes learn by them**

Organising and implementing a new disability policy

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

- I think I have provided this already in prior questions
- Much in the way of knowledge development is required much training around Person Centred/Directed Approaches
- Person Centred Active Support
- Changing mindsets of the community and families moving away from caring roles to empowering roles from seclusion to inclusion
- Increasing the standards and quality outcomes by increasing qualifications of profession
- Making Disability a High Standard Profession
- Support Professional bodies like National Disability Services and Disability Professionals Victoria
- Bottom up, Little to no Bureaucracy, Transparent, Family empowerment and inclusive, Respectful, Value Driven, Streamlined Seamless System, Quick response in case of emergency changes, Central Location of Resources, Openness to sharing of ideas and models of best practice and failures as learning models for others

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

- Unfortunately, it is required YESTERDAY but God made the earth in 7 days and man works slower than God so it will take greater effort
- Really, in the land of instant knowledge and communication the 'System' could be created via computers with programmers doing software. Small committees could be developed and delegated portions of policy and practice framework but these committees will also be required to collaborate periodically to create cross information and development of big picture.
- Representatives from all states need to be involved as this is a national roll-out project these representatives will be front people to roll-out within their delegated states and disseminate knowledge
- **Hopefully 1 year of dedicated work ethic could develop this scheme with the 'right leadership of individuals'**
- In the Interim: The economy works on people, companies and governments borrowing to grow their wealth and infrastructures **I believe that the Federal Government could set up an interim short term system with a fixed amount of \$\$ that will be allocated via seeking individuals in most**

dire crisis generally these would be ageing parents with ageing children at home to plan and implement future needs for this person 'What is a Home' so that in crisis this person doesn't end up relinquished in a hospital or respite facility due to parent health crisis or death.

- **Also I believe that more support is also required in the early days intervention support as parents are unable to cope with younger children with a disability and day care and primary schools are unable to support inclusion equitably NOTE the many stories in Victoria newspapers of families suing government due to lack of support in educational system for children with Autism and other disabilities**
- This \$\$ could be repaid back to government after scheme is fully started with continuous flow of income

In conclusion, while I have a daughter with a disability we are fortunate that her disability is not life threatening but it is invisible at times and people still have negative perceptions of her needs. As her prognosis is that within the next 5 years she will be fully deaf this will continue to change her needs and supports that she will require to be successful in educational endeavours, to be successful in work and to have people in the community accept that she may be communicating with non traditional modes like Auslan and other adaptive equipment.

Her 'HOME' will require various adaptive equipment for her safety and she will need to use the Relay Communication System. All of this will be costly and as her family we are not wealthy and presently worry to that we will have to approach untraditional financial avenues to gain support to have these modifications put in place for her. The scheme will provide this for her. Presently, she receives different models of hearing aids and micro link systems to use daily (when not in for repair) as no cost to us but present policy is that when she turns 21 this disappears. She will be required to support at her own cost all equipment she needs for daily quality of life. Hopefully, at 21 she will still be in Tertiary education of her choice but due to being a student she will not be able to fund her own supports and why should she.

It is my professional experience too that many more families are in worst situations than we are and I endeavour to support them as much as possible. I see the neglect and abuse that takes place within the system and within some organisations government funded and operated as well as non-profits. But, these organisations have traditionally been seen as institutional environments and never had to be accountable to anyone or anything. Staffing within these environments have traditionally not been of a professional nature with lack of knowledge and training which continues to promote bad practices and the devaluing of the profession.

Yes, transformation will be a challenge but some of the foundation of this transformation has already been put in place with policy and legislation even though it may need adjusting along the way. There is also other countries that have already embarked on this journey and we can learn from this and not have to start from the beginning and learn by all the same mistakes or make all the tools this has already been done for us we only need to adopt these into our own system. Training packages also have already been created in these countries which are eager to share their wealth of knowledge for us to adopt.

So let's grow and lead as a unified nation for the human dignity of all residents and create a sustainable system that other countries can then look to us to bench mark for best practice. We can then be the mentors and leaders NOT the followers.