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Disability Care and Support Inquiry
Productivity Commission
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PERSONAL RESPONSE - INFORMAL SUBMISSION

"The ONLY purpose of government is for the welfare of its people."
(Samuel Johnson - 18th century English Parliamentarian)

Dear Roberta and Commission,

I want to first address the most important question in regard to a new
National Disability Insurance Scheme...

01. HOW WILL IT BE FUNDED?

I suggest that there are more motor vehicles in *Australia* than people!!
Each of these motor vehicles, trucks, buses, and motorcycles has **Compulsory 3rd Party Insurance** to cover personal injury caused by vehicular accident.

I suggest...

This compulsory Insurance charge be paid into a National Disability Insurance Scheme and distributed as required. This will eliminate costly litigation and ALL DISABLED persons, whether born with, or acquired their disability later in life, would receive support services.

This funding alone will be insufficient and additional monies can be acquired through a **NATIONAL DISABILITY LOTTERY!** Australians love to gamble. So let's gamble on providing funding for **ALL** Australians who never know if or when they might become disabled!! After-all, life itself is a gamble!!

Note: The **government would continue** to add its normal Funding allocation.

Control, Assessments and Distribution of this funding will be the responsibility of State Disability Commissions.

02. OUR BACKGROUND?

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My wife and I are 74 years old and 40 years ago we adopted our only child who had been abandoned in hospital. She has a border-line intellectual Disability. We have lived in NSW, Qld and for the past 34 years in WA.

Our daughter married an Intellectually Disabled man 13 years ago and lives in a '**CLUSTER**' of 7/2-bedroom homes where all the residents are Intellectually Disabled. Management of property and provision of daily support services is by local Council. They rent for life as the housing project was built by Public Housing Authority.

I was a teacher's assistant for several years in a 'Special Ed School' and am an active member of various Disability organizations.

Our 40 years of slogging at the coal-face has provided considerable experience in PROBLEMS and possible SOLUTIONS – which is the purpose of this submission.

03. EARLY ASSESSMENT & INTERVENTION?

PROBLEM: Different states have different age limits!

SOLUTION: **Standardize age times** for early assessment and intervention so families moving inter-state, carry that same time-frame.

04. PORTABLE FUNDING?

PROBLEM: If family moves inter-state, their State Disability funding **is cancelled** and then they join the end of another queue for new funding arrangements!
State Funding **is cancelled** at 65 and is not portable into old age!

SOLUTION: **A NATIONAL DISABILITY 'WHOLE OF LIFE' INSURANCE SCHEME.**

05. THE AGED PENSION?

PROBLEM: The Disability Pension disappears & one is placed on the Aged Pension!

SOLUTION: Government to recognize that the Disability doesn't disappear with age!
Why not a **duel Disability/Aged Pension card?**

06. EDUCATION?

PROBLEM: Mainstream schooling is not for everyone.

SOLUTION: **Maintain and increase 'Special Education Centres' WITHIN** the boundaries of mainstream School grounds so there is some interaction between the groups and integration in some activities and classes.

07. OPEN-EMPLOYMENT?

PROBLEM: Mainstream employment, although desirable, is not always available, nor always wanted, nor always possible by all folk with Disability.

SOLUTION: **Increase alternatives** to employment as day care **ACTIVITY centres**, for crafts, outings, entertainment etc.

08. SHELTERED EMPLOYMENT?

PROBLEM: Over the years, some government people wanted to close-them down!

SOLUTION: **Maintain, support and increase Sheltered Employment.** Remember, not all people with Disability want to or are able to access open-employment.

09. FAMILY SUPPORTS and WHOLE of LIFE PLANNING?

PROBLEM: Too much reliance upon family to provide supports. **Families stress-out, burn-out, wear-out and finally fall-out** as aged parents despair! Some families have no relatives to assist! There are 'other' children w/o Disability needing Mum & Dads' attention!

SOLUTION: Government **INTERVENTION BEFORE FAMILY DISINTEGRATES!** This can be resolved by whole-of-life planning **BEFORE** disaster strikes!

10. LETTING GO?

PROBLEM: Aged parents are not 'letting-go' of their adult Disabled family member because adequate and appropriate services are limited. Living with ageing parents is not conducive toward healthy, 'normal' living for anyone!

SOLUTION: Early planning, with education of the family by encouraging parents to let-go with provision of '**enough**' funding for **INDEPENDENT** living at the appropriate age through a **National Disability Insurance Scheme.**

NOTE: Our daughter wanted independent living at age 18 and we were willing to **let-go!** We entered the funding **lottery fight** and after **8 years, we won!**

11. ACCOMMODATION & CONGREGATE CARE?

PROBLEM: Limited choice as one takes whatever and wherever is available!

SOLUTION: Increase **CHOICE** by proper planning with Public Housing Authority to build more **CLUSTER** housing of **PERSONAL CHOICE!** This would encourage **CONGREGATE CARE** that is more **AFFORDABLE** than **individualized funding, with the added benefit of having like-minded people (age & disability appropriate) living in a semi-independent environment that share company and eliminates loneliness!**
An added financial bonus is effective use of limited funding.

12. WHO Should be Eligible & Identified in New Scheme?

PROBLEM: WHO Indeed???

SOLUTION: '**ALL**' people assessed as Disabled and receiving a Disability Pension/Allowance. This includes people born with Disability and those who acquire Disability later in life.

13. Which Groups Are Most In Need Of Support?

PROBLEM: How to decide who is most in need can be unfair to those who require Disability support services but are overlooked because they don't have a critical need. **There is NO light at the end of the funding tunnel!**

SOLUTION: The new **National Disability Insurance Scheme** will allocate funds to **ALL** Disabled regardless of their level of Disability and eliminate the unfair queue, the horrendous wait-time and the stress of litigation!!!

14. MEDICAL CARE?

PROBLEM: Lack of specialists in Developmental Disability area.

SOLUTION: Renew efforts & funding to encourage practice in this area and **establish Specialists Practices.**

15. MEDICAL CARE in RURAL & REMOTE AREAS?

PROBLEM: Disabled folk have serious travel difficulties.

SOLUTION: Why not bring the medical service to the Disabled person? Years ago we had traveling salesmen – tinkers – knife sharpeners – medicine men hawking miracle cures – traveling dentists vans. I can remember them!

More realistically, if a person has a prosthetic leg or arm that requires a simple adjustment or re-measurement, why should they have to travel a thousand kilometers? Perhaps a medical person could travel with Flying Doctor or Flying Chaplains **bringing the service to the Disabled person.**

16. HOW to REDUCE WASTEFUL PAPER TRAIL?

PROBLEM: Multiple Government Departments want to do their own assessments in order to provide additional services. This is particularly true with Centerlink who has **little or no expertise in this area.** EG: The Carer's forms are 54 pages of complicated and overly intrusive questions in requesting private medical problems of the applicant, and **Breaching doctor-patient confidentiality.**

SOLUTION: The person with Disability could provide a simple 1 or 2 page Medical Document indicating their need for additional supports w/o public servants needing to know the private '**nuts & bolts**' of the Disabled Person!

17. CHARITY?

PROBLEM: Charity targets specific people and misses others with equal needs!
EG: A wonderful Charity paid \$25,000 so an amputee could have prosthetic legs after waiting a number of years to walk! Where will they be when he/she needs new ones? And, what about the other person who also needs new legs??? **They miss-out!**

SOLUTION: Charity funding should be used for things one might not expect to receive through government funding; such as, a spa, barbeque, gazebo, furniture!

18. LOCAL COUNCILS?

PROBLEM: Not enough agencies to provide services etc.

SOLUTION: **Involve Local Councils** in the provision of services, so that people with Disabilities don't have to move out of their area to find services.

19. MULTIPLE DISABLED PEOPLE WITHIN FAMILY?

PROBLEM: Double/Triple the issues-Double/Triple the needs-Double/Triple the cost-Double/Triple the stress- Double/Triple the tears- Double/Triple etc.

SOLUTION: **Double/Triple the solution and supports with ENOUGH FUNDING!**

20. MULTIPLE DISABILITIES?

PROBLEM: Separate agencies/doctors dealing with only one of the problems!

SOLUTION: A **SINGLE** agency providing **MULTIPLE** services to meet **all needs!**

21. MULTIPLE SUPPORT SERVICES?

PROBLEM: Lack of coordination and traveling to many agencies.

SOLUTION: Consolidate agency support. **Localised One Stop Shop.**

22. DIVERSITY OF DISABILITY?

PROBLEM: A person can have the same Disability, but one size support does not fit all!

SOLUTION: Recognize that not all people are the same and can cope with similar solutions. Provide **Individualized Care Programmes.**

23. ETHNIC DISABILITY?

PROBLEM: Language and Culture can add to misunderstanding!

SOLUTION: Better **training of carers and medical folk** (see item 22.)

24. ABORIGINAL DISABILITY?

PROBLEM: **Tyranny of distance** is only one concern.

SOLUTION: (See items - 15. - 22. & 23.)

25. CHALLENGING BEHAVIOURS?

PROBLEM: Needs no explanation!

SOLUTION: **Immediate and emergency 24 hour help with specialized support!**

26. RESPIRE ALMOST NON-EXISTANT?

PROBLEM: Limited places. Long wait-list. Can't access when needed.

SOLUTION: **All Local Councils to have at least one respite house.**

27. WHO SHOULD RECEIVE CARE?

PROBLEM: By determining the severity of Disability? When Family falls apart?

SOLUTION: Meet the need of **ALL PEOPLE REGARDLESS OF THEIR SEVERITY and BEFORE FAMILY FALLS APART WITH WHOLE OF LIFE PLANNING!**

28. WHEN SHOULD DISABLED RECEIVE CARE?

PROBLEM: "How many 24 year old men still rely upon their mum to lift them out of bed, toilet them, bath them, dress them, feed them etc?"

SOLUTION: **APPROPRIATE SUPPORT SERVICES ARRIVE WHEN NEEDED!!!!**

29. WHO SHOULD PROVIDE CARE?

PROBLEM: Far too many Disabled rely upon inadequately trained family, relatives, volunteers, friends, anyone, etc.

SOLUTION: We will always need them! But provide **FREE TRAINING!!**

30. RENUMERATION FOR CARERS?

PROBLEM: Carers undervalued and underpaid with the result that few enter this field of human endeavour as a life-time employment service.

Losing good workers seriously affects the person with Disability.

SOLUTION: **Take better care of the carer** with increased pay and better conditions.

31. WHO'S THE BOSS?

PROBLEM: The carer is not in charge and giving orders etc.

SOLUTION: Recognize that the person receiving support/care is the **EMPLOYER!**

32. WHO IS RESPONSIBLE FOR SUPPORTS?

PROBLEM: Differences between Federal & State governments & various agencies.

SOLUTION: Better coordination of services, funding etc. **One agency in charge!**

33. STABLE GOVERNMENT MINISTERS?

PROBLEM: **WA had 7 different Ministers for Disability Services in only 2 years! Families and Agencies are driven MAD with repeating themselves!**

SOLUTION: **This position should be for the life of that particular government!**

34. REVIEW DISABILITY BENEFITS?

PROBLEM: **Centerlink is a serial offender!** Every 3 - 4 months they require a review of Disability circumstances as families and carer agencies are required, under threat of losing benefits, spending a lot of time on **useless repeat paperwork! This detracts from us doing our primary care job!**

SOLUTION: Advise Centerlink that **disability is forever & for most, never changes!** A review is more acceptable every **3 - 5 years!**

35. ASSESSING ELIGIBILITY FOR DISABILITY SERVICES?

PROBLEM: Government only assesses the person with Disability and ignores the family situation! Eg: A single mum in a wheelchair was refused extra supports so she could look after her 8 year old son because he was not Disabled! **It was suggested he be fostered while she goes into a nursing home! HOW INHUMANE IS THAT?**

SOLUTION: **A bit of COMPASSION + COMMON SENSE + FUNDING = the SOLUTION!**

36. **CHANGING NEEDS?**

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PROBLEM: Once funded - it is almost impossible to obtain additional funding as health/Disability deteriorates!

SOLUTION: Additional assessments with funding as required!

37. **WHO AM I?**

PROBLEM: I am NOT just a person living with Disability!

SOLUTION: **I want recognition that I am a live, functioning human being who deserves respect and equality! I may also be a Mother/Father/Wife/Husband/Partner/Single/Adult/Baby/Child/Teen with dreams and aspirations for a full and fulfilling life, who just needs that extra loving support!**

38. **CHOICE?**

PROBLEM: Who decides where one lives? How and who provides these services?

SOLUTION: **It's MY Disability and MY life and MY CHOICE!**

39. **A READY RESPONSE RESCUE TEAM?**

PROBLEM: Barriers toward accessing services still exist! Go here! Go there! Where to Go? How to get there? Having a Disability makes that impossible for many! Families are under way too much pressure to address all the problems.

SOLUTION: Disability Services need to travel and bring their service to the person!
(See items 14. & 21.)

40. **MONEY?.....Is NOT the root of all evil.**

PROBLEM: **Never enough!!!** Costs keep increasing along with the need!!!

SOLUTION: **A National Disability Insurance Scheme!!!**

There is so much more, but I think I'll END it here!

If you read this paper.....**THANKYOU!**

PS: Your Comments Welcome

**Remember.... The year 2011 will be the 30th Anniversary of the Inaugural
INTERNATIONAL YEAR OF THE DISABLED.**

**The LOGO had a large 'A' promoting Ability instead of Disability and
The MOTTO was "Break Down The Barriers"**

William Sabin Booth

WSB
OK TO SHARE!

