Submission to the Productivity Commission

Mary Walsh – Community Advocate/Parent. **Dated 12th. July, 2010**

Pre-amble

My submission, as provided, covers a national and regional perspective – especially from the Wide Bay Burnett region in Queensland. This region is socially vulnerable, with a higher than average number of people with disability, the aged, and the unemployed . It also has a lower than average disposable income and a higher than average dependence on social welfare.*(Report for the Wide Bay-Burnett Regional Organisations of Councils and the Queensland Department of State Development, Trade and Innovation,* compiled by *the National Institute of Economic and Industry Research.2006).*

But this region is not vastly different to much of regional Australia..

I am the mother of an intellectually disabled son – deceased 6 years ago at the age of 40. In all those years we, as family carers, had to fight for every single service he ever received during the course of his life. On his birth we refused to accept the only option offered – "*put him in an institution in Brisbane and get on with your lives.*". Some people will always require some type of centre-based care, but I do not support large institutions.

My Curriculum Vitae is detailed in **Appendix 1A (confidential – separately supplied)**), and details 40 years of advocacy and representation of people with disability and their family carers at local, State, National and occasional International level. This includes my representation (as the founding president of Australian Parent Advocacy) of workers and their families on the National Disability Consultative Council, the AIRC investigation of wages for people in business services (previously called "sheltered workshops") and the development of the Business Services Wage Assessment Tool (BSWAT).

FORMAT:

SUMMARY OF RELEVANT ISSUES.

1. **Regional Australia:-** needs not often understood by policy makers (*Appendix 1 –p 17-18)*
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2. **"Carers"** - the various types (*Appendix 2- page 19)*
3. **Family Carers –** no legal rights
4. **Not-for-Profit service provision** - the shrinking "charity" dollar
5. **Lack of Uniform National Portable Guardianship Legislation**
6. **Early Intervention** - a must
7. **Service Provision - a business –** the paper war and administrative "run-around".
8. **Risks of applying successful overseas models** - the differences.
9. **"Silo-ing" of services –** current funding models
10. **Informal "networks" –** unknown and unlinked
11. **Multi-agency competition**
12. **Disability – "an entitlement" – not "charity"**
13. **Disability and premature ageing –** a case study
14. **Assessment tools** – and inappropriately trained assessors
15. **Integrating existing Federal Agency data**
16. **Mental illness – lifelong disability and episodic illness –** different departments
17. **"Social inclusion"** - ideological purists
18. **Poorly targeted information and education**
19. **"Transitional" life phases**
20. **"Premature ageing" –** a subset of disability – not of the "natural ageing process".
21. **"Family Relinquishment"** - an inhuman process
22. **Reasons for increasing incidence of disability.**

THE ISSUES – IN DETAIL

1. Historically, policy makers do not have a good understanding of the needs of regional Australia or the generalized delivery of services. It has been my experience that the decision-making processes do not encompass, in any depth, the tyranny of distance, the lack of services and a fair distribution of resources back to the areas of our nation creating much of our economic stability. Neither do policy makers always understand the boundaries of their legislation. This lack of knowledge can create "unintended consequences" for people outside the target group *(Refer Appendix 1 – case study – pages 17-18)* .

2. This Enquiry is about ***Disability Care and Support.*** Most of this care is provided by family carers and "support workers". The latter are commonly banded together under the terminology of "carers", which adds another confusing dimension. (*Refer Appendix 2- page 19)*

3 Those same family carers have no legal rights.

4 Additionally, Not-for-Profit organizations deliver many of the specialist services in an era where the 'charity" dollar is shrinking – especially in regional Australia.

5 There is no uniform, or portable, National Guardianship Legislation. If we accept that people with severe to profound disability – with their accompanying complex needs – are the priority level of eligible people, then they often require a legal decision-maker. More often than not, family carers are better positioned for this role than service providers and/or bureaucrats. Having been refused guardianship on my first attempt, I found the Queensland Tribunal to be rights-based and somewhat anti-family.

6 Early intervention is a critical factor in reducing the negative effects of disability. Although it lessens future demand, it has seldom been a priority for funding.

7 Service provision is now expected to be a well run business identity – with all the subsidiary paperwork for legislative requirements. Wages are poor and administrative requirements continue to make in-roads into service provision, with more emphasis seemingly on accountability and transparency than actual service provision

8 The possible implementation of an NDIS needs to adequately allow for the differences in the Australian psyche, as well as the size and decentralization of our nation, compared to successful models in smaller countries. Importing processes from smaller regions, with insufficient modeling, can introduce an additional problem when some of these countries – in size – are but a fraction of **our** geographical area.

9 The fragmenting and “silo-ing” of services is aggravated by the current funding models, and the creation of further barriers by departmentalizing within various larger Departments.

10 There is insufficient use or knowledge of existing informal “networks” within Australia. **Refer confidential Appendix 2A- (page 21).** A significant amount of good-will from the private sector, as well as localized communication and education resources remain untapped because decision-makers have never linked all those local networks efficiently – or never bothered to know of their existence.

11 There can be significant inefficiencies and waste created by multi-agency competition. This often suits government funding allocations and decisions – to the detriment of consumers, their families and carers..

12 Disability should not be about resources – it is a rights-based issue. Neither they, nor their family carers want pity or sympathy. They do not want welfare – they want what every other Australian has – an entitlement.

13 There needs to be formal recognition that many people with life-long disability age prematurely. In fact it is often a feature of more recently diagnosed “syndromes”. Yet, achieving access to federally based aged care funds is thwarted by the Federal Government insistence (ACAT) that incontinency is more an indicator of age than “premature ageing” which, to my knowledge, has never been accepted as a criterion for eligibility to Federal funding . My own son, as part of his disorder, was prematurely aged at 35yrs. of age – it was a medical part of his syndrome. Had he survived he would not have been eligible for any Federal funding under the “aged-care” guidelines for a further 30 years.

14 The application of any eligibility tool for a disability – or result of disability – should ensure assessors have the requisite skills and experience Using a rehabilitation assessor (e.g. to assess the productivity of someone with lifelong disability in a business service- cannot provide any accuracy if the assessor’s only experience has been with aged persons – or recuperating persons of normal or temporarily impaired intellect). There is a big difference between aged care and lifelong complex disability, even if there are some similarities.

15 There has to be a more efficient way of applying known (and available) Centrelink data to individuals with lifelong disability. Enormous duplication and waste – not to mention additional stress for family carers – exists with current never-ending requests for notification of changes to the capabilities of the person receiving the Disability Service Pension. The form needs to be filled out and returned to Centrelink within a specified frame-work – or they lose their pension. Surely those who cannot be “repaired or rehabilitated” could be “flagged” on the system. As a parent I was subject to extra stressors when I received this regular paper-work. My son could not get to the office, without me – it had to be business hours, or phone - but the 132717 number takes forever. Accountability for public funds is one thing – but simple

systems would decrease current waste. With the best will in the world, and the most positive attitude, my son was destined, forever, to be a recipient of the welfare system. He was not expected to live past 2 years of age, but he was the pivot of our family lives for 40 years. Sadly, he was never going to "miraculously" recover and a stream of paperwork to confirm this was repetitive, wasteful and an inefficient use of existing technological data.

16 Current definitions of disability and mental illness fail to identify mental illness, as distinct from lifetime disability, as episodic, in some cases. This creates barriers between competing budgets, at different tiers of Government for disability and health. When a person has multiple disability, including a component of mental illness, they are "shunted" between Federal and State Government agencies, and between Departments within Departments, each protesting it is not their responsibility. This is a repeat of the current "premature ageing" debacle.

17 Australia's current social policy focuses on "ageing in place" for the elderly and "social inclusion", with the same rights as non-disabled citizens, for people with disability. Sadly, social inclusion was taken to extremes by some ideological purists, who, because they were well organized, and often funded, drowned out the needs of their more vulnerable counterparts, and it has taken over a decade for the pendulum to start swinging back into balance.

18 There needs to be better targeting of information. There is the assumption, by Government and providers, that everyone is computer literate, so the use of hard copy is fast becoming obsolete. Often those most in need of information and education may not be computer literate, or have access to a personal computer – particularly the ageing. These people often rely on local "networks", and the whole of Australia has a system of Local Governments. Both of these existing resources are ignored in the bigger picture, resulting in inefficiencies and poor targeting of scarce resources.

19 There are "transitional" life phases for people with lifelong disability, just as with the non-disabled community. The difference is that "leaving home and getting a job" in community terms doesn't always happen for people with a disability. These disability "transitional" phases are greater times of crisis than they often are for their non-disabled counterparts- because the services are not there, and parents lose their legal rights once the disabled child is legally "adult" – though not mentally competent.

20 Disability is usually congenital or the result of trauma at some stage in life. Premature ageing should be a sub-set of "disability" – not a sub-set of "the natural ageing process"., which can be readily identified by medical assessment.

21 Relinquishment of a family member – under the age of 18 (legal adulthood) - is an inhumane process, at least in Queensland. Relinquishment to the State is usually not because families are **unwilling** to continue caring – but **unable** to continue

caring (This is because the existing system forces families to continue caring – despite the impact on the family unit – until breakdown point.). My experience has been in the period of adolescence. The responsibility of providing services is a State one until the child is 18 – when they are automatically entitled to Federal assistance and also have supported employment options, if considered capable. The presumption is that, being (legally) adults they have DSP entitlements to help them pay for day activity services which, as a State service – should be readily available !!!!!. Some of these adolescents would never have survived infancy without current medical technology and have profound disability – non-verbal, non mobile,(wheelchair dependent) tube fed, non communicative, incontinent, prone to epilepsy, abnormal sleep patterns, and require medical aids for lifting etc. The quality of care and love of family has extended their limited life expectancy, but they often have complex medical needs which the family understands better than anyone else because they have been doing it for years, often with no / or very limited access to services and respite. When the family simply cannot cope beyond endurance the only option remaining is "relinquishing, or abandoning " them to the State. This process then places them into the Department of Child Safety, which accepts responsibility for the funds required to provide the additional supported accommodation costs – outside the family home- It should be remembered that these families , in many cases, have other children, and employment responsibilities. The "relinquished/"abandoned" child is then considered for foster care, which doesn't necessarily even have to be in their current community.

Legal responsibility then transfers from one Department to the other, but requires a full legal process of the parents being "served with papers" and seeking a "protection order" before the Court system The child is now, legally "abandoned", and in "need of protection" because of that family abandonment. This is an emotionally destroying process, with the parents having to deal with their appearance before the magistrate, the court-room processes and overwhelming sense of guilt. In both cases, where I have supported the families, even the child safety officers ended up in tears, because the love, care and responsibility was immediately obvious and no one could understand how these families did it for so long (ages 14 and 15 years). Being made to feel like a criminal, when they should have been given a medal, is soul destroying, but the services are then provided by another Department. In both cases we obtained non-custodial protection orders which allowed the family to continue their health attorney status, the adolescents went into community care, with their peers, were much happier - just like any non-disabled teenager. – and the outcome was positive. But, it shouldn't have been "that" inhumane, and the process has to be humanized. These families simply couldn't cope any longer – both lived some distance from the city – but would have, and wanted to continue their role, if only the necessary services, respite, transport, emotional and physical support had been available. They were not **"unwilling**" to care – they were "physically,financially and emotionally **unable** to care."

22 Disability is increasing due to

- Improved medical technology, which now means that people with disability are living longer

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- More premature babies now survive at an earlier age, but often with significant disability
- Infant disability is also increasing as the incidence of mothers with substance abuse giving birth is now more prevalent.

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- The family structures in society have changed with families now more mobile and moving away from the family home to pursue career options. This reduces the availability of family carers.
- Family carers are ageing. They are often in need of care themselves, but many still care for their own ageing parents.
- The incidence of “term-of-life” disability is increasing with more trauma survivals from motor vehicle accidents and increased family pools survival from drowning incidences.

RESPONSE TO KEY QUESTIONS

Questions	Answer
Who should be the Key focus of a new scheme, and how they might be practically and reliably identified	The key focus of eligibility should be those with lifelong disability and complex needs. Acquired disability presents a slightly different focus, depending on the age and circumstances of on-set. Some might come with a compensation package – others might not. Identification should be from existing data, using an individualized approach – subject to review, and should include premature ageing which results from the disability. Disability is either life-long or acquired. If it is life-long and genetic then there has to be acceptance that premature ageing because of accepted disability is distinct from the natural ageing process In earlier days people didn't live long enough for premature ageing to become medically or physically obvious.*(Point13).* The current problem is the distinct barrier for this latter group because aged care is a Federal responsibility and prior 65 years is a State responsibility. This is a reverse position of the criteria for business services,(Federally funded under employment), which must now be productive and have a business "profit". This criterion forces many would-be attendees back onto a State funded day-service. So both levels of Government are "gate-keeping" their departmental budgets to the detriment of the person with disability. I would contend that "premature" ageing – when it is a medically accepted fact - is an integral component of their life-long disability and should be accepted as a sub-set of life-long disability. Any national scheme would centre the funds federally, but, as services would continue to be delivered by the States, this existing anomaly must be acknowledged and incorporated Identifying eligibility should be an easier and less complex system than currently, and **should utilize the existing data** *.(point 15.),* Litigation paranoia now pervades Governments and service provision due to privacy legislation which is utilized to the nth. degree – often an avoidance measure. Centralized data, with a national scheme, should be lessened if existing data is reliable, and disability education better targeted to those most in need.

Which groups are most in need of additional support and help?	Ageing people with disability being cared for by ageing family carers, when the latter are in need of care themselves. The mentally ill (*Point 16*) Those inappropriately placed in aged care facilities. Families caring for more than one child with a disability. Young carers Families with new-borns Those in the "transitional" life phases of disability.*(Point 19)* i.e. infancy, education, adolescence, post education, adulthood and ageing. These phases place people with lifelong disability at the behest of different levels of Government, new assessment processes with a multitude of different agencies (*Refer Diagram 1- page 20)*with parents losing all legal rights when the disabled family member reaches the legal age of 18
The kinds of services that particularly need to be increased or created .	Supported accommodation with several models • Cluster housing • The prematurely aged and those who are ageing and want to "retire". • Young care – those inappropriately placed in aged care. Respite to help family carers cope for longer, and provide alternative experiences for the disabled person. Early intervention Post school options. Better interfacing between existing Federal agencies – i.e. Medicare, Centrelink – including more efficient use of the existing facilities Investigating and using existing local "networks", including the Local Government linkages, to better use local community goodwill.

Ways of achieving early intervention.	The new scheme needs to build in a specific targeting of funds for early intervention. Governments and service providers see no immediate benefits in spending scarce resources on services with no immediate performance outcomes, especially when reporting is outcome focused. The benefits, as we know, are long term. Early intervention funds should be a separate sub-set of the whole fund and the moneys should be used for that purpose only. Consistent historical reporting would establish “trends” and performance indicators. This would better sell the process to decision-makers and providers because this is the best measure to reduce welfare dependency. Therapeutic services – i.e. speech, physio etc. are essential components of early intervention – but there’s “no money”.
How a new scheme could encourage the full participation by people with disability and their carers in the community and work.	There needs to be an acceptance that “full participation” for some will never be possible because of the complexity of their needs, so a blanket scheme of participation is impossible – especially in regional areas. Participation could be improved if transport was more available, but participation should always be based on the needs and circumstances of each individual. Education and local networking would help and these should be more readily available at existing agencies – Centrelink, Medicare and Hospitals. Currently these agencies are “silos” – on which the person and their carer is dependent. The old friendly family doctor no longer exists, but no alternative has been provided
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.)	Establish more accessible independent systemic and individual advocacy systems. Early intervention and respite do empower family carers. The current system – nationally – ensures that, if a family can cope – no matter the degree of difficulty or impact – then the system makes families cope, until they fall apart. An inadequate service is better than none – and many families are forced to accept that. Greater flexibility, and less rigid complexity in the allocation of funds for services, provided there is adequate reporting and retention of data

Establish National Uniform and Portable Guardianship Legislation.

Ensuring there is a national legal system of re-dress – i.e. Adult Guardian, Public Advocate

Learning from the lessons of the past

How to improve service delivery – including co-ordination, costs, timeliness and innovation.?

Accept the system is now irreparably “broken” and hopelessly inadequate.

Introduce a National Disability Insurance Scheme, where funding will be produced and centralized.

Ensure the current Commonwealth States and Territories Disability Agreement is reviewed.

Where possible cut down on the duplication and wasted resources. It is a matter of history that R2R funding (Roads to Recovery – local government) from the Federal to Local agencies (by-passing the States) produces greater efficiencies.

The Medicare agencies (accepting that regional Australia does not have the same access as urban Australia) are well run and generally efficient. Disability specialists could be a part of the existing structures of Centrelink/Medicare and deliver cost and efficiency benefits.

Better “network” linkages, improved targeting and education at all levels of the “transition” phases.

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

As with all public resources it is a fact that “the squeaky wheel gets the oil”.- especially if their campaign becomes publicly vocal..

The highly vocal and well organized lobby groups make some decisions a foregone conclusion.

Well written submissions, by paid professional writers, influence decision-makers. Not every applicant can afford to hire some-one professionally. Well written applications make it easier for the decision-makers, especially when accountability and transparency feature highly in the criteria.

The most vulnerable, especially if exhausted family carers are "hanging on in there"- are the most likely to be overlooked. Family carers are often too exhausted to become involved in lobbying, and are fed up with having done so for many years with so little result for their previous efforts.

The process of obtaining funding is too complex for the average family carer, as are the accountability and reporting requirements.

Inadequate knowledge of what is available.

Some conflicts of interests –inter-organisationally- can ensure some people get excellent services, while some others get none – or basic.

Some decisions are politically motivated – for political benefits in certain regions.

The most vulnerable – "*the too-hard basket"* do not have the same promotional and media marketing benefits for decision-makers. Consequently, the community in general knows very little about the high needs, the personal costs and financial imposts of severe to profound disability.

Much as we choose to deny it – there is still a stigma – at the broader community level for the mentally ill and profoundly disabled.

Perhaps, in changing the focus to **A**bility, we have done a disservice to the most vulnerable. While this is slowly improving we have a long way to go

How to ensure that any good aspects of current approaches are preserved?	You need to know which ones they are – from the gathering, and retention, of data, community, consumer and family feed-back. “Good aspects” must have guidelines which can be blended into the new system, but this cannot be a blanket approach. Good aspects should be performance based – be that consumer outcome, financial efficiency, community and/or family benefit. Individualised funding, (per se) which provides an AI service for one person, but presents inequities for others, should be re-visited.
What to do in rural and remote areas where it is harder to get services?	Decision-makers need to understand the differences in individual communities. All communities have networks – find out what and where they are and tap into them. Where possible make disability a sub-set of an existing service or network. Capitalise on the pride and human endeavour of these communities. They provide wonderful examples of “self-help” and community “glue”.
Reducing unfairness, so that people with similar levels of need get similar support	Assuming that people with similar “levels of need” get similar support , does not accurately reflect individual circumstances. Family carers comprise many types of “blended” families, and the double income family is now a common fact of Australian life. There are also many families who have more than one child with a disability. “Levels of need” need to be individually assessed in relation to established individual circumstances – not a perceived notion of “fairness”

Getting rid of wasteful paper burdens, overlapping assessments (the “run-around”, and reducing duplication in the system.?	Previously included in other responses
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.?	Use of the taxation system, similar to the existing Medicare-utilizing their existing facilities, where possible Use existing data to provide an estimate of existing, and future need, allowing for the increasing incidence of disability as previously listed. A “no fault” system to reduce wastage of funds in litigation costs. Tax incentives for individuals – this could include extended families, as well as direct families. Tax incentives for corporate Australia Encourage siblings to assist with care by providing study incentives. Current requirements for tertiary study set defined hours of work. – documented “care” should be considered equivalent “work” hours.
The practical aspects of a scheme that will make it work, such as how existing arrangements would fit into a new scheme, how to manage risks and costs, and ideas for attracting people to work in disability services.	By running both systems parallel until all the transition and practical administrative “bugs” are ironed out, and the new system is bedded down. Investigate other legislative requirements – as previously detailed – CSTDA, National Uniform Guardianship in the interim Commence dialogue with representatives of local governments and regional communities to identify regional needs, with particular attention to those in more rural remote Australia

Engage the indigenous community in the dialogue. The current age threshold of 50 is to the detriment of some individual indigent persons. This defined “age” provides no flexibility and allows State providers to place such persons in an aged care facility, even if their needs would be better served by a rehabilitative program.

The new system, once bedded down, could then be progressively rolled out to new recipients, with those on the old system being reviewed so their circumstances are consistent with the new scheme.

Workers in the disability sector now lack a good career path and wages, for the work required, are not considered sufficient inducement to stay in the sector. Consequently the sector now suffers because of high staff turnover and insufficient training, which can be detrimental to service quality and consumer outcome.

There should be an appropriate degree course, with subsidiary certification and diploma levels for those in the hands-on delivery of services. Wages need to be commensurate, and the current use of volunteers to assist with supervised activities is a good way to give the community ownership.

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How long would be needed to start a new scheme?.

Rolling out a new National Disability Scheme requires a solid background of behind-the-scenes organisation.

- Where will it sit within the existing system?
- Who will it cover?
- How will it be funded – for now, and for the future – and still run parallel with the existing system.
- What other complementary legislation needs to be in place prior to rolling out the new system.?
- What level of education and marketing is required – for taxpayers, for users of the current system.
- How to identify existing networks and other possibilities for corporate and local government involvement?
- Taxation incentives – and necessary legislation -

The unknown factor is political willingness to make it happen but, once that is accepted – by whomever – then nothing less than 5/7 years would be needed to progress it from that point. Allowances must be made for the political processes of the

. three tiers of Government – none of which have concurrent time-frames.

It is not often understood by anyone who doesn't "live disability" that family carers develop an understandably unique mechanism to cope with the daily requirements of providing care for someone with complex needs; look after other children and run the family home… I did it myself.

You try and ensure that you have the where-with-all, the energy, the attitude, to cope day-by-day.

"Just let me get through to-day – to-morrow might be better – there might be a service, my child with special needs might, unexpectedly, improve.

I've just got to get through to-day – to-morrow is another day, and I'll worry about it to-morrow. I can't look too far ahead – I've just got to cope with to-day."

I recently addressed a meeting of young families. One young mother – with a profoundly disabled daughter – aged 3yrs.- had a disabled cousin, and I had known them all since childhood. Her comment, when some of the family carers questioned why they should be more forward—thinking, when they were flat-out coping with to-day, was as follows:-

..”Mary I was at meetings, as a child, when you were making similar statements about the care of my disabled cousin, and I can't believe that nothing has changed in those 30 years.

We would like to think that we would not be standing in your shoes, 30 years from now, trying to help another generation of parents.

No one expects to have a child with disability – that's something that happens to other people…not you.

How wrong we were!!

Powerful words – but true.!!!!

Only the introduction of a National Disability Insurance Scheme – running parallel with ....Centrelink/Medicare/ Hospitals,Communities and Corporate Australia.........................
will change that likelihood.

APPENDIX 1

Issue 1 Policy-makers lacking practical knowledge and not understanding the impacts of their new policies – and legislation.

Case Study:
The Queensland Planning and Development Department introduced new legislation known as “The Building and Other Services Legislation” (BOLA-). This was introduced to tighten the Fire Safety standards of hostels and back-packer accommodation following the loss of 15 lives in the tragic fire at Childers (near Bundaberg) in 2000.

The legislation became law, but there was no consultation with the disability sector – especially family carers. Local Government was instructed to inspect and enforce the new legislation on all group housing, and it was made retrospective to existing buildings after a certain date, and all new buildings in the future.

The “unintended consequences “ of the lack of practical knowledge by the department was that the legislation “caught” all group housing because it related to buildings which housed in excess of 5 – 10 residents. All rooms were to have self-closing doors if they were at a particular distance from exit doors, there was to be no more than 1 door (this ruled out screen doors) at any entrance or exit point. These doors were to remain closed at all times of the day and night to provide a “safety wall” in the event of fire.

Hospitals complied because they have existing “self-closing” doors which can be automatically over-ridden if required. Overnight, almost all of Queensland’s residential housing for people with disability whose circumstances required 24 hour support from live-in support workers was in jeopardy. The doors had to be fitted, retro-fitted in most cases, by a date that was now law, and the Queensland Government was not willing to change it. - should there be a tragedy, then this would represent a legal risk for them.

Providers had to comply, so Queensland families began a 2year campaign to have the legislation amended.

Residents, who had previously been able to leave doors open, if they chose, benefitted from the cool breezes and congenial fellowship of a common community room, were now forced to have their rooms fully closed off at all times of the day and night. It took 2 years to get the necessary amendments, cost hundreds of thousands of $’s as providers were forced to comply under threat of legal liability and/or prosecution, and turned these community homes into mini-institutions. Air-conditioning was not an option due to prohibitive costs, and the residents – many for health and safety reasons, needed 24 hour supervision and/or support. This was almost impossible when all of the doors, including those of the live-in supervisors - were forcefully closed – at all times – in the middle of 2 Queensland summers.

But! – the self-closers went in, at a considerable financial impost – screens came off, illuminated “exit” signs went in, extra doors, where necessary and at least one building had to be totally replaced.

All of the residential housing had sprinklers, fire alarms, fire management plans and safety drills, but this was considered insufficient, even though there was no history of fire.

It was all about possible litigation – as much as safety – but the net cast by this policy – which quickly became law- impacted severely on the State’s most vulnerable citizens. Overnight they became prisoners in their own rooms (homes).

The Childers experience had seen litigation instigated against the owners of the hostel, the Council and the State Government because some of the doors were blocked off, fire alarms turned off and there were no sprinkler systems.

There was little doubt that the ill-informed legislation, with its impact on the residents, created an abuse of human rights, but it was families who had to do the fighting to get it changed. As far as the Government was concerned – it was law, and had to be implemented.

When the legislation was finally amended more money was spent to replace the “self-closing” doors, and the situation, in most cases, reverted back to the previous. The Government had to provide funds to cover some of the costs, and some air-conditioning was introduced.

The amendment campaign came at considerable cost – in energy, frustration and stress – for families. It wasted scarce resources because it was State law, which had to be implemented under Local Government law. Their refusal to implement would have placed ratepayers at risk should there be a tragedy.

So, the doors went in – at a cost – then, 2 years later came out – again at a cost – all because policy makers “didn’t realize” this group of people would be affected. The law placed these residents at considerable health, safety and personal risk – because the policy makers did not consult, or understand the impact of their own policies on people they profess to support

Considerable problems exist when policy -makers operate in a vacuum, and don’t do their homework

APPENDIX 2

“Terminology” and its implications.

There are many different types of “carers:-“

“Life-time”	*carer*	*a disability from cradle to grave.*
***“Time-of-life*”** -	*carer*	*usually the frail aged- whose caring needs (statistically) span a period of 5- 10 years.*
“Term-of life”	*carer*	*usually a disability acquired at some stage of life, genetically, medically or through trauma*
“Foster”	*carer*	*The caring role is one of choice.*
“Young”	*carer*	*The role is performed by a child/ adolescent*
“Paid”	*carer*	*properly termed “support worker”, but generically included as a “carer”.* *Unlike other carers they have workplace and choice entitlements*
“Wild-life”	*carer*	*An optional choice of caring for animals*

Now we seem to have “*wilderness”* carers, protecting nature and the environment. This is not to demean the valuable role played by all, rather to provide practical examples of the generic nature of the terminology. The move to the generic acceptance of the term “carer” was (historically) purely administrative – for ease of welfare and bureaucratic analysis and entitlements. It was strongly fought by parents and families at the time – to no avail.

This administrative trend blurs the various roles of all types of carers, and many of them do it tougher than some others.

Any National Disability Insurance Scheme needs to be conscious of terminology. The types of care are different, its impact on family carers is different, even though profound and severe disability are relevant to all (except wild-life and wilderness). Having been both a “life-time” carer (our intellectually disabled son – deceased 2004) and a “time of life” carer (my mother – deceased 6mths ago at age 100)). I am of the opinion that the whole disability sector (now an industry) is hopelessly broken and needs total replacement.

Diagram 1

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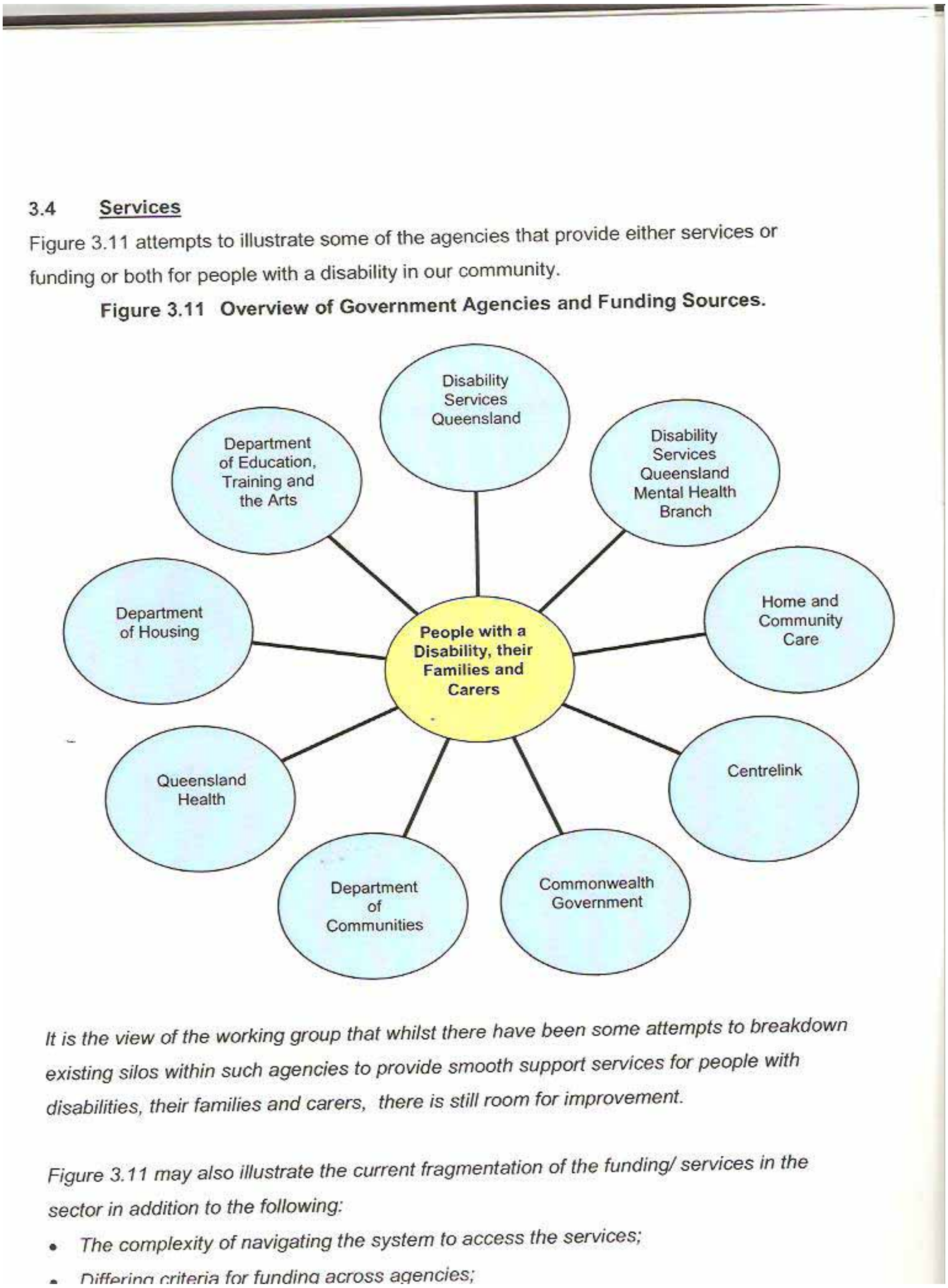

3.4 Services

Figure 3.11 attempts to illustrate some of the agencies that provide either services or funding or both for people with a disability in our community.

Figure 3.11 Overview of Government Agencies and Funding Sources.

It is the view of the working group that whilst there have been some attempts to breakdown existing silos within such agencies to provide smooth support services for people with disabilities, their families and carers, there is still room for improvement.

Figure 3.11 may also illustrate the current fragmentation of the funding/ services in the sector in addition to the following:

- *The complexity of navigating the system to access the services;*
- *Differing criteria for funding across agencies;*