

Mrs MARY WALSH OAM

29 July, 2006.

The Secretary,
Senate Community Affairs references Committee,
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Canberra ACT 2600

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The following submission addresses the Terms of Reference which form the basis of your Senate Enquiry into the Funding and Operation of the CSTDA.

This submission reflects my understanding of the impact of intellectual disability on the person with the disability, the family carer, Governments involved in the delivery of care, and the wider community. My understanding is based on 40 years of advocacy as a parent/carer of a person with an intellectual disability (lifetime), who is now deceased (aged 38 yrs.)

As a parent/carer my submission reflects the views of thousands of families – Australia wide. As a family carer, professional accountant and qualified financial adviser I represented the Federally appointed National Family Carers Voice as one of the bodies consulted in the preparation of the CSTDA Report. My CV forms a separate attachment, and is provided on a confidential basis

My other experiences, over the 40 years have been as

- 1 *Co-founder of Australian Parent Advocacy Inc – a national, self funded group for people with intellectual disability, and their families. This body is now being wound down, hopefully to be replaced by funded representation, which is more realistic than what has been available to-date. This group previously had a membership of almost 2000 family carers, plus a corporate membership which represented most of Australia's service providers.*
- 2 *The representative of workers in business services (previously sheltered workshops) before the Australian Industrial Relations Commissions, and, before that as their representative on the National Disability Industry Consultative Council.*
- 3 *An independent advocate for the needs of this disadvantaged group of people with a disability.*
- 4 *A member of numerous State, Federal and Local Advisory bodies to all levels of Government, Research and Academia over 40 years..*
- 5 *Someone who cares and has lived disability through my own life, and the lives of many others.*

Whilst the needs of all people with a disability are acknowledged, it is those with more significant needs, and their family carers, who are the most significantly disadvantaged. The system means they have to struggle with the inadequacies of multi-layers of Government, bureaucrats, deficient reporting and the lifelong stress of caring,

The CSTDA has (historically) catered for the needs of people with a disability but, as people with a disability are now living longer, and their family carers are ageing (and often in need of care themselves), there is a critical need for the parameters of this funding to be critically evaluated.

My comments are made as the parent carer of an intellectually disabled son for 38 years, and my aged mother for 34 years. My son passed away 2 years ago, but we had to fight for every service he needed. He was 28 years old before we were able to access some form of supported accommodation to assist us and, after 10 years on the waiting list it only happened because of family illness assessed as terminal.. My mother will be 97 years of age next month – and she has only now, after 13 years, secured a place in an aged care facility.

In that time we have reared 3 other children and, whilst we loved our son dearly, and fought to provide him with the best we could, I would not wish him back. He was a victim of an inadequate system and so were we – his family.

The CSTDA is critical to the lives of this disadvantaged section of our community, and my comments reflect my personal and advocacy views and life experiences.

Sincerely,

Mary Walsh

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ASA, AIFS, JP(Q).

BASIS OF RESPONSE

This response to the Terms of Reference is predicated upon the following background: -

Disability is increasing due to: -

- Increasing live premature births – often with increased long-term and severe disability
- Increased accident rates due to increased mobility of the population – i.e. more traffic accidents and incidents of trauma.
- Increased disability at birth resulting from foetal exposure to drug and alcohol addiction
- Increased life expectancy for people with disability due to improved technology and treatment.
- Increasing incidence of autism and other disorders which are evidenced by “challenging behaviours”, but not factored into services at all levels, by all Governments.

This increasing cohort of people with disability is occurring at the same time as the Families and Carers, whom the Agreement recognizes as playing a pivotal role are

- Ageing (often in need of care, themselves).
- Experiencing the social impact of increasing marital breakdown, the blending of family structures, and the increased impacts of distance as families are now more geographically widespread. Family carers are now subject to expectations their care role precedes all obligations to other, also needy, family members.
- Exposed to a lack of services because Governments are devolving much of their service provision role to community organizations, which are usually inadequately resourced. What was once a disability sector is now a disability industry, which is not obliged to formally recognize the role of family carer.
- Devoid of options for services as de-institutionalisation was inadequately resourced and Governments insisted that care was to be provided by community inclusion and/or families. No, or few,

centre-based services now exist for mental illness and intellectual disability resulting from genetic, trauma or other forces.

This response also needs to accept that: -

- Family carers are now in crisis (An extensive 4 year study by the National Family Carers Voice supports this statement),
- Family carers have no effective method of communicating their needs to the various levels of Government,
- Family carers have no legal recognition or rights.
- The needs of the person with the disability and the family carer are, sometimes, different – but are inextricably linked.

Advocacy is a critical role for family carers of people with decision-making disability. Other forms of disability can be accommodated by medication and/or equipment and are not fully reliant on the provision of a lifetime of support and/or advocacy.

Intellectual disability is either "*whole-of –life or term-of-life*", but this type of disability often excludes them from participation in the development of services, policy and funding programs. Family carers are often exhausted from their care, and other family roles, so lobbying for both recognition and funding remains the province of those less incapacitated. The end result is sometimes non-representative of those with higher needs.

Consequently, people with more severe types of intellectual disability, and children with "challenging behaviours" are often relegated to the "too-hard basket". Therefore, they are under-represented in the funding and advocacy models.

An understanding that this premise is the basis of my response, on behalf of thousands of families, is critical to understanding the response given.

RESPONSE TO TERMS OF REFERENCE.

1 The intent and effect of the 3 agreements to date.

The CSTDA Annual Public Report 2002-2003 advises that :-

“The agreement underpinning the CSTDA is a shared vision that in Australia, governments work co-operatively to build inclusive communities where people with disabilities, their families and carers are valued and are equal participants in all aspects of life.

Families and carers meet most needs of people with disabilities. Services provided under the CSTDA support the pivotal role of family and carers”

Those of us who, as family carers, fought for the introduction of the Disability Services Act, 1987, and the subsidiary State legislation support the vision (intent), as stated, but question, very seriously the effect of the CSTDA.. If the Agreement is ineffectual then the vision (intent) can never be attained.

This Agreement purports to provide the resources needed to complement State funding, accepted by the States when all disability services, except employment (and part printing/advocacy) were devolved to the Australian States.

The Agreement will continue to be ineffectual unless, and until,

- ❖ The pivotal role of supporting family and carers is clearly defined – across all levels of service provision.- both State and Federal – and within the CSTDA
- ❖ The definitions of “advocacy services” and “family carers” become an integral part of the Agreement.

Currently “advocacy services” (*Part 3 –Interpretation - 3(1) – page 7*) means “*services designed to enable people with disabilities to increase the control they have over their lives through the representation of their interests and views in the community*”. This does not recognize the “pivotal” role of family carers for those with life-time intellectual disability. Legally, once an intellectually disabled person (irrespective of the level of disability) turns 18 years of age, the family carer has no legal rights, even though they might be providing 100% of the care. Guardianship is not easily given by any of the States. Indeed no uniform guardianship laws exist, nationally. My personal experience in applying for guardianship was a nightmare – I was initially refused, because it would have taken away my son’s “rights”, and given me “control” of his life – which rightly belonged to him. In practice, the “representation of the interests and views of people with severe intellectual disability in the community” is deemed to be better held by anyone other than the family carer. The definition of “advocacy services” in the Agreement perpetuates this practice, because it excludes any reference or definition of family advocacy.

Equally the definition of “Carers” makes no mention of whether the “carer” is paid, or unpaid. The use of the terminology “carer” has been expanded for ease of Government administration purposes. It has been an encompassing – and strategic acceptance that, in terms of the existing definition it is “*someone, such as a family member, friend or neighbour, who has been identified as providing regular and sustained care and assistance to the person requiring*

support". However "carers" can now be "life-time carers (cradle to grave)", "time-of-life" carers (aged care – generally 5 years); "term-of-life" carer (disability acquired at some time in the person's life, often from trauma, genetics or illness); "young carer" (a child caring for a disabled parent/family member); a "foster-carer"(someone choosing the role, and able to relinquish at any time. This "carer" is afforded greater rights and resources than the natural parent), a "paid carer" (support worker, who receives all industrial rights and can enter and exit at will. We now also have "wild-life" and "environmental" carers. They are all called "carers".

If the Agreement is to deliver on its mission for advocacy and carers (i.e. provide a pivotal role of support for families and carers) – then this should be better defined. Broadly, family carers are experiencing a subservience of their role to the needs of the service provider (based on inadequate resources – at all stages of the disabled person's life) and the "rights" of the person with a disability, even though that person is intellectually incapable of exercising either control or responsibility for their actions, and they remain in the full care and responsibility of family carers..

- ❖ The pivotal role "of supporting family and carers" is accepted by those responsible for funding decisions – at all levels of Government.
- ❖ There is an holistic approach to whole-of-Government, in practice, not just theory, which minimizes duplication, provides clear pathways inter-departmentally and is outcome focused – not rigidly budget-driven
- ❖ Services are adequately resourced, and provided on the basis of need and ideology – not solely ideology.
- ❖ There is an acceptance that prevention is better than cure i.e. – early intervention is critical to long term management, and assists both the person with a disability and the family carers. This covers all areas of life – infancy, education, adolescence, adulthood and old age. This acceptance has a dollar, social and community service value.
- ❖ Acquittal of funding is more transparent and accountable.
- ❖ There is a national register of unmet need and a mechanism to adequately measure projected need
- ❖ There is a national average standard of care/support – with an average dollar value – per capita – which all States are obliged to meet.

2. The appropriateness, or otherwise of current Commonwealth/State/Territory Joint funding arrangements, including an analysis of unmet needs and, in particular the unmet need for accommodation services and support.

Current inter-governmental funding arrangements are based on the implementation of Federal/State social policies which are ideologically sound, but realistically unachievable and financially (and morally) inequitable.

The amount of unmet need continues to grow, as the number of people with a disability increases, - at both ends of the spectrum - and family carers age. There would be some proportionate relativity, also, to the increasing growth in foster carers. The latter seem to have replaced the centre-based care which previously existed. Few people would have argued for retention of the institutionalization system that existed, but Governments continually refuse to consider some form of centre-based care – smaller and more personalized – for those in need of supervised and supportive accommodation arrangements.

This has just been evidenced by the Prime Minister’s allocation of federal funding for people with mental illness and his comments that “we closed down the institutions, but didn’t put anything in their place.” The same scenario applies to people with intellectual disability.

This historical failure to provide smaller, more personalized centre-based services has compounded the unmet need for the previously existing population, and deprived the current and future populations of much needed services. Consequently, a refusal by State Governments to provide any form of supported accommodation (4-6, maximum 8) seems to be the norm and this provides some excellent services for a few, with very basic – or no – services for others.

This purely ideological approach provides no economies of scale, incurs extra cost for support workers in travel, duplicates management costs and is an inefficient use of scarce resources.

Consequently, families faced with the new birth of a family member with significant disability must now provide for that child, in their own home (with support, which is inadequate and sporadic), and deal with the extra financial and emotional burden, the impact on siblings – or surrender the child to foster care, thereby relinquishing all rights – simply because they cannot cope.

The alternative is “in-home” or “host-family” care – which doesn’t work well, in most cases. Invariably the home becomes a work-site, subject to workplace, health and safety legislation which is simply over-the-top and families have actually been sued for compensation for “work-place” injuries (incurred in their own home by support workers).

Children (termed “young carers”) are increasingly being called upon to provide care and support for their disabled parent, and this is often at a cost to their own future, their education and social position.

So, a failure to recognize the impact of Federal and State social policy on disability continues to produce a growing volume of unmet need – in respite, early intervention, supported accommodation and day services. The thrust of federal policy requiring business services (previously sheltered workshops) to compete with private enterprise and become viable,

sustainable businesses, has forced State day services to pick up the fall-out as part of their day services.

Therefore, a Joint Government funding arrangement, based on social policy which is undeliverable without a massive, and recurrent, injection of extra funding, raises the question of whether this Senate Enquiry accepts we should only address funding. If we accept this is all about funding, without exploring the further dilemma of whether the implementation of the social policy, upon which the funding arrangement is based, requires further analysis, then we do an injustice to those people the Agreement is commissioned to protect.

The current Terms of Reference, however, do not permit such an analysis. In the absence of such an analysis, I conclude that the growth of unmet need is directly linked to:-

- Increasing incidence of disability.(previously explained)
- Longer life expectancy of people with a disability.
- The ageing of family carers.
- Social policy based on ideology and vision, but increasingly under resourced as the nation tries to “catch-up” and provide, *simultaneously*, for the increased need. This is particularly relevant to “challenging behaviour” disabilities which are inadequately provided for in the infant, education and adolescent phases of their life, and consequently require more physical and financial resources as adults.
- An increasing “expectation” mentality that pre-supposes “Government will provide” – in accordance with the policy of the day, and there is increasing lobbyist and advocacy power to ensure they do. This is often to the detriment of those most in need (and their family carers)
- A blurring of the parameters between ‘the disabled’ and the “selectively unemployed” – which increases the cohort of “disability”
- Increased litigation and insurance costs – associated with Workplace Health and Safety and public liability. This has removed community and volunteer resources from the equation of “care and support”. In turn this impacts on family carers and service providers. This consumes more financial resources and turns a “met” need, even if not perfect, into an “unmet” need.
- A failure to recognize the role of volunteers, and a growing expectation that there should be some “financial reward” for such services.
- A continued abdication of Governments, as service providers, to the charity and not-for-profit sector who, in turn, struggle to compete for the charity dollar. The higher the cost, the fewer the services and the end result is a surge in unmet need.
- A lack of understanding, by Governments, that information, advocacy and community cohesion assist people with a disability, their family carers and their communities to cope. Unmet need can be a direct result of an inability to cope with crises – which can be of a

short, medium or permanent time frame. An assumption that everyone can access the internet is unrealistic, and information and advocacy services should be available regionally.

- Any analysis of unmet need should establish a basic standard of the acceptable differences between a “poorly met need” and an “unmet need”, and how the latter is prioritized.

Unmet need is prevalent in all States and future Agreements should contain a performance outcome mechanism which identifies unmet need, gauges its prioritization and records it on a yearly basis. This will ensure funding is used appropriately, and that there is sufficient information to provide for future planning and the apportionment of adequate resources by both levels of Governments both now, and into the future.

Unmet need in accommodation and support is directly linked in the implementation, by all States (Western Australia is slightly more realistic) of a social policy based on individualized services for a privileged few to the exclusion of basic services for many. In between these two extremes is a cost efficient, cost effective and equitable method of meeting that need, but this will not happen until the States are forced to accept the reality as a condition of their funding.

2 The ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap.

Whilst both Governments verbalise the existence of a whole-of-Government approach – it doesn't exist. This is because the “siloining” and “compartmentalizing” of departments, senior personnel and budgets within the various Departments sustain the current dysfunctional approach.

Special reference is made to aged care and health, but the problems are much more widespread. Problems exist in all stages of the life of the person with a disability, especially if that person has a decision-making disability, has multiple disability and/or the disability is lifelong and of such an extent that they will require care and advocacy all their life.

It is critical that there is an acceptance of the difference between caring for a person who is frail/aged and one who has a disability. Disability is usually accompanied by premature ageing but the level of disability is resulting in the increased use of nursing home facilities (aged care) for people needing permanent care in a medical/semi-medical model of care. This is particularly relevant for people who acquire degenerative disability – i.e. MS, or Motor-Neurone, whilst still relatively young.

There are serious administrative problems in the delivery of services, and funding (one is dependent on the other) because of the jurisdictional overlap (and the names change depending on which State you are dealing with) of responsible departments and budgets.

At Federal level disability is administered by FACSIA, DEWR and Health and Ageing. When a person with a disability is of pensionable age – they suddenly lose their disability and are just “aged”. Happens overnight!! A reasonably healthy person of 65yrs. has considerably different needs to someone who has a life-time or acquired disability – but the system doesn't recognize that. Additionally, Carers Australia – the body funded to represent ALL carers over the lifetime of the caree, is charged to represent both. Home and Community Care (mostly aged) is delivered by Health

and Ageing, but social policy is based on community/family care for both disabled and aged Australians.

There are too many buckets of money, allocated to too many Departments – and it just doesn't work. It is too easy for bureaucrats to “pass the buck”, at both Federal and State level by saying “it's not our responsibility”, so family carers – and service providers – are forced to work their way through a maze of different departments, each jealously guarding THEIR budget – to the detriment of the person seeking help.

Early intervention, so critical to improving the quality of life for the disabled person and their family carers, early in the piece, is constrained by the need for collaboration between Health, Education, Housing, and Centrelink.

A person with a mental illness is classed as “disabled”, but much of the mental health funding comes from Health – disability comes from FACSIA.

It's a minefield, and I'd like to make some positive suggestions but, each department will guard its budget to the detriment of others. All I know is that it creates massive inefficiencies, duplication and over-management. In the end, no one wins.

A separate portfolio for disability, at both Federal and State level, would provide a consistent and seamless transition from birth to aged care, and certainly provide more accountable and transparent use of funding

3 An examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

As a consumer of services I am not in a position to comment on this Term of Reference other than to say:-

1. Governments espousing community and business inclusion do not have a good record in either employment or procurement policies involving people with disability.
2. In examining alternative arrangements, please ensure that the discussions include consumers of services, as well as family carers, who have had to live the system. Far too often the consumers chosen cannot accurately reflect the difficulties encountered by those with more severe levels of disability – and/or their family carers.
3. I'm aware that the US has some good procurement policies (business services), and that the United Kingdom now has some better recognition of the role of family carers, and the needs of people with life-long intellectual disability.
4. Please ensure that the discussion participants understand the different needs of the frail aged as distinct from those with disability, and their family carers.

Family carers, sadly, live, breathe, eat and excrete disability. It rules their lives and the lives of their other family members. They can inject a pertinent viewpoint into any discussion on disability whether it's funding, administration, policy or services.

This coming Agreement will control the lives of thousands of families and people with a disability, dependent on them.

Thank you for the role you are playing in trying to get it right.

Signed.....Mary Walsh