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Submission

Productivity Commission Disability Care and Support Inquiry

2 June 2010

Background

This submission is made draw to the attention of the Commissioners the need for analytical rigor when considering what purports to be advice which can be relied upon as representative of the experience and views of people with disabilities and their families.

This submission has as its basis response to the 2009 report of the National Disability Strategy Consultation, *Shut Out: The Experience of People with Disabilities and their Families in Australia.* The *Shut Out* report was in fact informed by a very small number of people: using as a benchmark there being around 4.5 million Australians with disability, a mere 2500 people attended 58 open consultation meetings held around Australia. Around 750 submissions were received, 330 from organisations and around 420 from individuals. However, based on experience of what happens in Victoria, it is extremely unlikely that many of the organisations consulted widely and openly with their membership to ascertain their views on the National Disability Strategy.

By way of comparison, the public submission process for the 2007 Carer Payment (child) review taskforce received 4,086 submissions, the majority of which were from individual carers; organisations provided 23 submissions. One hundred and fifty invited people attended 27 meetings: 19 focus groups and 8 targeted consultations.

For the *Shut Out* report, none of the submissions were made public, only a list of organisation names was published. There was no analysis of the geography of the response ie how many from each State or Territory and no analysis of who attended the public meetings.

The report's revisionist spin on basic historical facts and generalised conclusions created from individual experiences has resulted in an emotionally charged report that presents more of the same deficits that have been known and articulated for years. While purporting to report the experience of families, the report barely gives recognition to the experiences of families of individuals with a disability and fails to fully explore the many hurdles faced by families and the significant role played by them in supporting their family members with a disability.

This Response first discusses a number of misrepresentations; second, highlights the report's failure to fully acknowledge broader system and community realities; and third, presents seven elements that must be addressed if the purpose of a National Disability Strategy (NDS) is *"... to map out what we need to do to start fixing problems." p v.*

Essentially, the writer submits that if the National Disability Strategy – which is meant to include a possible new funding scheme - is to provide the platform on which a rights approach to disability is to be built, then this can only occur if the current model of resource rationing is replaced by a right to service. The writer acknowledges that the scope of the Terms of Reference for this Inquiry makes mention of assessing an approach which provides long-term essential care and support for eligible people with a severe or profound disability on an entitlement basis. The writer intends to make a separate submission addressing eligibility and entitlement.

1. Misrepresentations

i. The Span that is Disability

The *Shut Out* report unfortunately tends to generalise the individual expressions as though they necessarily represent the views of most. However, it cannot be ignored that those responding to the consultation have by virtue of their contribution demonstrated an ability to articulate their concerns. And, although their individual contributions should not be devalued, it cannot be ignored that the respondents only represent what might be described as the tip of the iceberg. They do not necessarily represent the many individuals whose level of disability is severe or profound, are multiply impaired and who do not have the ability, even with high levels of support, to self advocate, live independently or ever hope to participate in meaningful employment, let alone respond to a consultative process such as that established by the National People with Disabilities and Carer Council (the Council).

Almost since the inception of the concept of normalisation in the 1950s, through to social role valorisation, deinstitutionalisation, to the latest catchwords *social or community inclusion*, the advocates of such concepts have promoted them as though the boundaries of an individual's ability and potential, no matter what the limitation, have little relevance.

While the *Shut Out* report would have us believe the world of disability is one where all people with a disability have the same capacity and potential, this is not the reality. Therefore, until such time as there is full acknowledgement of the existence of those who represent the core and the base of the disability iceberg; people with severe and profound disabilities or multiple impairments; the misrepresentation that promotes community inclusion as the panacea will continue to be promulgated.

ii. Families as the Significant Providers of Service - Then and Now

Since the concept of deinstitutionalisation gained prominence in the 1970s, the disability purists and the self-appointed protectors of 'rights' have laboured a continued attack on the ills of such a service model, to the point where it has become counter-productive in that it is backward looking and a distraction from today's issues.

The writer argues it is important to at least acknowledge that almost up until the last two or three decades of their existence institutions provided the only real alternative to the residential care provided by families of people with a disability. Indeed, even when other services began to come on stream in the 1950s, generally it was families who took the lead in establishing what were commonly known as day centres, play groups and early intervention programs.

Thus, whatever the arguments for and against institutions, the fact is they were a product of government, their continued existence was a determination of government, and up until well into the second half of the twentieth century they were generally the only service provided by government for people with a disability.

Apart from what appears to be a convenient reference to institutions as *shutting people in*, apparently in order to give a literary emphasis to the report's title *Shut Out,* the fact is, even at the height of their accommodation numbers, institutions only ever provided service to a tiny fraction of people with a disability, and then generally only to people with an intellectual disability or mental illness. By misrepresenting the facts the most important point of all is ignored, that being, it has always been and continues to be families who provide the bulk of support to people with a disability. By ignoring this, the report ignores the fact that families of people with a disability may well continue to be marginalised when the strategic directions for disability services are articulated in the proposed ten year plan.

The reality is that this almost mystical entity referred to as the disability system ignores most people, under-services those who do have access to it, rations the little that is available, and generally cost-shifts to the vast brigade commonly referred to as families of people with a disability.

iii. The Concept of Specialist Services

An interesting observation in relation to the issue of specialist services for people with a disability versus generic services is that while some of the report's contributors argued for greater access to and inclusion in those services generally available to the rest of the community, at the same time a call was also put for "*improving disability support and services".* Sadly however, this call fell short of promoting the retention of, and need for, specialist disability supports and the provision of facility based disability services for those who can best benefit from this service model.

Over recent years many philosophical purists have called for a move away from specialist service provision and facility based services as well as a cessation of the small group home or Community Residential Unit (CRU) model of accommodation. Although the report highlights there are many people with a disability who would benefit from greater access to generic services and housing models, it fails to adequately acknowledge those who are not at the tip of the iceberg, that is, those who can best benefit from and require high level specialist supports and facility based services.

It is somewhat ironic that at a time in our history when there has never before been so much specialisation, whether in areas as diverse as medical services or vehicle maintenance or other goods and services, there are those who condemn and argue against specialist disability services. These people instead suggest that all the needs of people with a disability can be met by generic service providers. Nonsense! It is debatable whether generic service providers meet the needs of people without disabilities.

While individual support packages may for some provide the best option, the report fails to note this is not necessarily the preferred option for others. Packages can add to the burden of an already over-burdened family and add little value if in reality the services and support required are not available, inadequate or precluded by geography.

The Rudd Government's funding for specialist early childhood services for Autism Spectrum Disorders provides a clear indication that if the NDS is to truly represent the broad ranging needs of all those with a disability, as opposed to select groups, then it must recognise that generic services will not be the answer for all.

iv. Integration, Inclusion and the Community

Much is made about isolation, segregation, lack of access and how people with a disability are not socially included in the community. While the writer does not deny the significance of the difficulties of physical access and social engagement, he challenges any suggestion that specialist services provided for people with disabilities are somehow not part of the community. He argues that the community is in essence the sum of its parts. Too often, as suggested by the report, the community is represented as being entities and activities other than services for people with a disability. Too often there is the inference that social inclusion is the panacea for addressing the ills of the disability system.

v. The National Conversation about Disability

The writer notes the Chair of the Council suggested that one of her first jobs as Chair *"... was to begin the national conversation about disability" p.vi.* This is somewhat disconcerting, as this statement seems to suggest that desperate families and people with a disability have neither sought to be heard by successive generations of politician, bureaucrats and people in positions of power and influence nor sought to have their pleas for services included as part of the conversation of disability.

The essential questions therefore are: What will be different this time around? And – How will the Council and those in positions of power and influence translate the talk festivals, the consultations, the myriad of documents and high sounding statements into real live service provision?

After all, despite the listening and wise nodding in the past, the real challenge has always been how best to provide a service which meets the needs of all those who seek it. This challenge still exists today and must be surmounted if the NDS is to be hailed as a success.

vi. The Concept of Ownership

In some ways the significance of the two questions above raises the issue of what might be called ownership. In the context of the disability system and its underpinnings, the report fails to fully acknowledge that the Federal Government does not have ownership rights over disability. At best it provides some funding support through the National Disability Agreement, is responsible for employment services and provides pension and allowance benefits. The significant areas of transport, education, the built environment, health, accommodation, in-home support, day services, a range of other support services, and the bulk of advocacy and information services are funded and operated by the States and Territories. Therefore, although the report makes reference to *“adopting a national approach*” and the NDS not being seen in isolation and ensuring “*there is coordinated and comprehensive planning across all portfolios and between all levels of government.”,* the fact that the Federal Minister and Portfolio Secretary do not have any directive power must be seen as a potential weakness of an NDS.

vii. The Utopia Accessed by the Rest of the Community

Throughout the report there is frequent reference to people with disabilities requiring the same access to health, education, recreation and sport and a range of other services and activities as all others in the community. In promoting this notion, as the report tends to do, the suggestion seems to be that there are no other cohorts of people in the community who are also, as the report’s back-cover suggests – *forgotten, neglected, hidden, rejected, excluded, discriminated, abandoned and isolated*.

The harsh reality is that no matter what the barriers faced by many people with a disability, the same barriers also face many other cohorts in our society. Our society is not, as the report infers, a utopian society for all others. The significance of this misrepresentation is that by potentially isolating itself from acknowledging service and access deficits confronting many other groups are essentially the same as those facing people with a disability, then the NDS may fail to acknowledge the potential opportunities available through government initiatives in the non-disability sectors. Initiatives such as those listed in the report of the National Health and Hospitals Reform Commission, state based public transport initiatives, developments in state operated educational systems and the new Fair Work legislation.

2. Spin, More of the Same and Systemic Realities

i. An Office of Disability for Co-ordination

Why is it, that the creation of yet another 'office' or bureaucratic entity such as an Office of Disability is seen as being necessary to *"coordinate efforts across portfolios and between levels of government"*? The problem of unwieldy bureaucratic structures will never be fixed by creating yet another box on the structure. An example of unwieldy and unnecessary structures exist in Victoria where in addition to Disability Services which is a program in the Department of Human Services, the government also saw fit to not only then create another separate entity for disability but to locate it in a different department.

The adage that recognises responsibilities must be paired with the necessary budget, an authority to direct, and if required a coercive power, is ignored in a coordination model. The disability pathway over recent years is littered with failed partnerships where coordination has been the *modus operandi*. An attempt to coordinate within a single jurisdiction is complex enough, but to suggest that it is workable across multi jurisdictions, in the writer's view provides false hope.

ii. The Realties of the Workplace

The report suggests that, *"Programs and services were built around organisational and systems needs rather than the needs of clients."* While the degree to which this might be supported at the individual service outlet level is debatable, what is known is that in Victoria when parent initiated day services were established, the services were built around the various needs of individuals with a disability and their families; they were not systems and organisation focussed.

However, while it is probably accurate to suggest that program and services are now increasingly built around organisational and system needs, the real question to be asked is – Why is this so? The real answer is that principally this is because services provision regardless of location and by whom; whether government managed, provided by the funded sector or a generic service provider, in a private home or in a residential service, constitutes a workplace. As with any workplace service providers are required to meet legislative, regulatory, policy, industrial awards, and requirements such as Occupational Health and Safety.

Additionally, increasing bureaucratic dictates and form filling that require huge amounts of time and are a cost subtraction from funds allocated for service provision, now prevails. Therefore, rather than making it easier for people to access the service system and navigate their way, the bureaucratic processes and systemic requirements are becoming increasingly cumbersome and confusing.

Thus, the systems failures are not usually as a result of the service providers, but are imposed by governments and industrial bodies.

iii. Critical Thinkers and Subject Experts

The writer notes with a degree of bemusement the suggestion that the next stage in developing the NDS will be to draw together "*Critical thinkers and subject experts ... to develop innovative strategies and actions to tackle identified priorities.*" The writer is bemused by this statement for three reasons. The first is the elitist subtext conveyed by the statement. The second is that by inference it suggests that critical thinking and high level knowledge and understanding are restricted to a few. But thirdly, and of most concern is the fact that many of those who might be deemed to be critical thinkers and subject experts are the very same people who for many years have been on the committees and the Ministerial Advisory bodies, policy makers in government departments or paid consultants to government.

They are the same people who have promoted the purist line through their academic treatises and policy statements, and they are the same people who have used their protected funded advocacy positions to promote the line of the government of the day. To the writer's knowledge none of these people has sought to promote the concept of an entitlement to service. And, while many have been quick to express their criticisms and concerns about the woes of the disability system, in many cases they are the very same people who have been responsible for its funding, establishing the policies that guide it, and allegedly representing the voice of the people who require services.

The writer raises concern that only those who are considered as capable of articulating their experiences and thoughts are included as subject experts. As noted by the submissions to the report it seems reasonable to suggest that only the orally articulate or those capable of making a written response contributed. Therefore, in selecting subject experts from the ranks of the disabled and their families, it is essentially that those who need to be supported in making a contribution and their families are not inadvertently shut out of the process.

The writer suspects however, that the critical thinkers and subject experts may also be the usual suspects from the preferred pool of academics, policy isolates and representatives from the funded advocacy careerists. It therefore must be asked - Who among the new batch of critical thinkers and subject experts will be new and fresh? And, for those who are selected from the old guard, what will they bring that will make their input more successful this time around?

iv. Another Plan

One of the intended products of the NDS is the production of a Ten Year Plan. The concept of a Ten Year Plan is of course not new; Victoria first went down this path in the mid 1980s, and then more recently established the *Victorian State Disability Plan 2002–2012* which was described by the then Minister as*, "... a hallmark of the Victorian Government's policy."* Now we have this latest proposal, where such a plan is proposed as a significant outcome of the NDS. Plans, more plans and yet even more plans seem to have become an essential element and almost faddish preoccupation in the disability industry. Individual Plans, Person Centred Plans, My Plan, Ten Year Plans, strategic plans, a plan to get on a waiting list and so the list goes on.

While not denying the importance of planning, identifying goals and establishing a strategic focus both for the individual and the service, the reality is the act of planning runs the risk of becoming an end in its own right. Or, the contents of the plan simply become a marketing tool to promote the wonderful things the particular government proposes some ten or twenty years down the track. This being despite the fact that election cycles in this country tend to rotate in three or four years cycles, and budget approvals are made on an annual basis.

If of course, plans such as that proposed in the NDS are so effective in creating efficient and effective service systems, or fixing broken ones, it seems reasonable to ask – Why, after one Ten Year Plan and a second two thirds through, is the system in Victoria as part of the overall national system, broken? What therefore, will the NDS Ten Year Plan be able to do that other similar plans have not?

v. The Matter of Attitude

The cry of recent years about the need for community attitudes towards people with a disability to change, and a greater level of awareness about disability to be pursued, came through as being alive and well in the report. While not condemning such sentiments as not being worthy of some comment and supporting such objectives as worthy of recognition in a long-term vision statement, the writer nonetheless argues that to become preoccupied with such objectives is both futile and a distraction.

In reality, negative and don't care attitudes, limited or no knowledge or blissful ignorance is not limited to the disability sector, and to infer that it is misses the point. The problem with becoming preoccupied with attitudes and awareness is that it becomes a distraction for what is the real game. It also provides a convenient out for governments who simply refuse to show leadership and legislate for an entitlement to service. The lack of opportunities do not come so much from the attitudes of the community and lack of awareness, but arise from the fact that there are not enough funded services to meet the demand. Therefore, the system creates service access being rationed on a so-called priority basis. This in turn leads to the needs of many remaining unmet, many of those who have a service having their needs under-met and only a few actually receiving what they need. Therefore, the focus of the NDS should not be to look for a convenient scapegoat in the form of attitudes but instead to place the lack of opportunities squarely at the feet of the Federal and State Governments.

vi. Oh Dear! The Vagaries of Social Engineering

The report's conclusion that community inclusion represents "*one of the great social policy changes of the 20th century"* smacks of one of those 'bigger-better' type statements trotted out by governments and spin merchants. In this case the real issue, on which the report fails to make comment, is two-fold. In the first instance the dichotomy is not between institutions and community or social inclusion, but more importantly a statement of the effectiveness or otherwise of two service models. One, the medical model as evidenced in institutional settings and the second the social model. While the medical model has been widely condemned for decades as having failed, given the closure of institutions has now been in vogue (at least in Victoria) for nigh on a quarter of a century, and by contrast, if not in name through various iterations community inclusion has been promoted over that time: Why is the system still broken to the degree that it is?

The reality is, community inclusion is not a policy paradigm, but instead a philosophical nicety that is underpinned by a desire of those who advocate it to engineer how we as individual and as a society should think and act – a classic example of the 'do as I say' approach.

Our society is not naive, it is very much aware that no matter how much the political and policy elite try and engineer changes in community behaviour, the challenge that will always be made will be, 'Put your money where your mouth is!" Fixing the broken disability system will not occur through the catchcry of social inclusion. Fixing the broken disability system is a hard-nosed high-cost entitlement issue. Until this is recognised it will remain broken.

vii. A Word on the United Nations Convention on Rights of Persons with a Disability

The writer notes the pride with which it is stated that Australia was one of the first countries to ratify the UN Convention, and how this Convention "*will be part of the Australian Government's broader long-term commitment to improving the lives of people with disabilities, their families, friends and carers*." Ratification carries with it much more than mouthing the sentiments and writing the high sounding statement into a glossy document. . As noted by the UN Convention handbook for parliamentarians, *"...establishing a right is not the same as ensuring that the right is realised",* and neither is it the same as States providing, *"... appropriate enabling environments so that persons with a disability can fully enjoy their rights on an equal basis with others*".

A recently published statistic puts the number of children known to be abused or neglected each year across Australia at over 300,000, this being despite Australia being committed to the UN Convention on the Rights of the Child. This figure highlights that simply being a party to a convention is no guarantee the intent of the convention will be realised.

Therefore, if the report is to ensure the UN Convention is written into the NDS then the NDS must also ensure that an entitlement to service is ratified.

3. The Essential Elements Necessary to Fix the Broken System

While the report lists four strategic priorities the NDS should address, each one presents as a soft generalisation: increasing the social, economic and cultural participation of people with disabilities and their families, friends and carers; introducing measures that address discrimination and human rights violations; improving disability support and services; building in major reform to ensure the adequate financing of disability support over time. None represent a hard hitting articulated 'must-do' type statement. The following seven elements are must-do actions if the NDS is to have any credibility in terms fixing the broken system.

i. A Single Piece of Legislation

Although the NDS is to be driven by coordination based on a common strategy the parties to this approach are subject to individual and different legislation across the Federal and State and Territory jurisdictions. Unless the NDS, through the Federal Minister and Parliamentary Secretary in conjunction with State and Territory Ministers work towards creating a single piece of legislation, the multiple service systems will continue to be required to pursue their own legislative requirements.

While it might be argued that the intent of the various legislations is similar and complementary and there are degrees of commonality, and as the report mentions "*governments cannot work in isolation*" and "*real long-lasting change will only be achieved in partnership with business and the community.",* the reality is that when it comes to funding services, articulating policy requirements, or establishing the gate-keeping for entry to the services system, government departments and bureaucrats play by the rules set by legislation governing their particular jurisdiction.

The writer therefore submits that unless a single piece of disability legislation is created for the whole of Australia, the NDS will be built on a bed of sand. Indeed, although the concept of a single piece of disability legislation may be shunned as unworkable, perhaps such a concept may be quite novel and refreshing in a country often hog-tied by multi-layers of at times conflicting legislation and associated regulation. Indeed, such an approach might just reduce the wastage and duplication as referenced in the report.

ii. Legislating a Right to Service

Despite the many high-sounding words written and spoken about the importance of rights, and despite reference to the UN Convention and Australia's ratification of it - The crucial missing link is the failure of politicians, advocates, academics and other in positions of power and influence to pursue the concept of a right to service. Before the cry of 'it is not possible' is raised by the protectors of rights, let us not forget that entitlement does exist for other groups.

Unless service entitlement is included in Disability legislation, the current rationing of services based on a nebulous relative needs approach will continue to promulgate the existing broken system

iii. The Separation of Adults and Children

Although the Victorian Disability Act 2006 purports to provide the legislative framework for all disability types and age groups, in its 242 pages the words child or children are mentioned only three of four times. This Act only gives lip-service to the rights of parents of children with a disability and it fails to make any reference to early childhood services, health services or educational services for children. Although only reflecting the case in Victoria, the writer suggests that it is reasonable to conclude that a clear distinction between children and adults is unlikely to be so in other jurisdictions.

The writer submits that the NDS must recognise the distinction between children and adults with a disability, and therefore ensure this distinction is enshrined in the NDS by promoting separate legislative provision as well as a children's focussed service system.

iv. Real Choice

The report made reference to choice as a fundamental freedom which few people with disabilities are able to exercise. It failed to note however, that while choice is promoted by governments, policy makers and advocates as something that should be available to people with a disability, the experiences in Victoria make a lie of this promotion. As an example, the Victorian State Disability Plan 2002 -2012 *"reaffirms the rights that people with a disability have to live and participate in the life of the Victorian community, with the same rights, responsibilities and opportunities as all other citizens of Victoria."* Yet, since 2002 there has not been any increase in residential services, other than for those people exiting institutions. Indeed there has been a condemnation of the small group home or Community Residential Unit model by many of those in positions of power and influence. The concept of housing similar to aged care villages, or the new housing development concept of gated-communities is shunned, and hostels and small modern amenity institutions are not to be mentioned, despite these accommodation models being available to other sections of the community. Thousands of adult people with disabilities have no choice but to live with their parents. The parents have the Clayton's choice of either abandoning their sons or daughters or providing support and accommodation.

The concept of real choice by way of alternative service types must be promoted as a must in the NDS, and the NDS must condemn the narrow, self-centred thinking of the philosophical purists and advocates who seek to deny real choice in service options.

v. Funded Family Advocacy

The report's reference to families of people with a disability is cursory and fails to fully acknowledge the part played by families in the provision of support and care. Interestingly, while the report promotes the "*provision of funding increases to advocacy and other non-government agencies to participate in the monitoring and evaluation of the strategy",* it fails to promote the notion of funded family advocacy. That is, funding for an advocacy entity or entities consisting of family members of people with a disability and managed by them to advocate on behalf of those family members with a disability and the family. Although it will be argued by some, that there are among the current batch of funded advocacy agencies those who represent families, the facts speak otherwise.

When considering families in which there is a multiply impaired disabled family member, the latest report on disability in Australia, released by the Australian Institute of Health and Welfare, *Disability in Australia: multiple disabilities* reveals some disturbing evidence that indicates the cohort of families in which there is a multiply impaired family member are side-lined. The report notes that in 2003, half of all Australians with disability, or about two million people, had a combination of two or more disabilities. It further noted the more disabilities people had, the more likely they are to need help with 'core' daily activities such as self care, mobility and communication. Disturbingly, the report also found that people with multiple disabilities who need very frequent assistance with daily activities are much less likely to have their needs fully met. And further, need for assistance shows a substantial proportion of care for people with multiple disabilities is provided by their family members and friends.

The writer submits that the NDS must be upfront in recognising the role played by families of people with a disability. It must therefore pursue the funding of specifically targeted family advocacy. Not to do so will continue to cast families as peripheral to the service system.

vi. The Economics of Having a Disability

Although the report addresses to some degree what the writer defines as the economics of having a disability, by discussing pensions and the establishment of some form of universal compensation scheme, it fails to address some of the flow-on effects of disability policy and the concept of fees charged by funded disability agencies and generic services.

The report fails to highlight that by promoting the concept of community inclusion and reducing specialist disability services and promoting access to user-pays generic services, the advocates of such an approach are essentially supporting cost-shifting to people with a disability and their families. By using the sleight of hand called individualised support packages as a substitute for specialist disability agencies; those who fund disability services are essentially condemning people with a disability to remaining in the family home and condemning their families to a continuation of providing unpaid labour.

The report fails to highlight the impact that policy has on the economic independence of people with a disability and their families. Thus, any fixing of the disability service system will be only partial, unless the impact of policy and practices on the economics of the individual is fully recognised. And therefore, given the aim of "*improving disability supports and services*" and "*building in major reform to ensure the adequate financing of disability support improving disability over time.",* the NDS must ensure that those services funded specifically to provide specialist disability supports do not seek to then charge for their services by way of fees.

vii. Community Inclusion and Communities of Choice

Community inclusion and its more recent extraction social inclusion have become the catchcry of the modern day advocates, bureaucrats and politicians. It is as though the terms alone offer the panacea for fixing all the ills of the disability industry. The way in which these concepts are promoted is nonsense. Those who wave these terms as a banner of hope fail to mention or acknowledge five critical considerations.

The first is, none of us live in a single community; each of us access multiple communities, for example family, social, work, sport, interest, service and personal. The second, the broader community, or in other words our society is a composite of the total of its parts. Thus, to suggest specialist disability services or institutions are not part of the broader community is equivalent to saying entities such as boarding schools, hospitals, women only gymnasiums, or kindergartens are also not part of the broader community. The third reason, reality dictates that entry into many entities within the broader community is criteria specific. Thus, just as not everyone it the community will play sport at the elite level or be eligible to enter university, equally, not everyone is eligible to receive a defined disability service or access particular pensions. The fourth reason is that to suggest individuals and entities can be forced by legislation to genuinely socially include others, where they may be of a different ethnic or cultural background, a different age cohort, a different social standing, or indeed they may be with a different capacity or potential, is little more than Orwellian.

But probably the most important reason of all is the concept of choice. That is, as individual we should not be forced into participating in entities, activities or with others if that is not our preference. The NDS must promote community inclusion as the inclusion of specialist disability service provision, and social inclusion as the inclusion of those social activities in which the individual with a disability chooses to engage; and not those manufactured by a so-called policy.

Concluding Comment

This paper has not sought to criticise the views of those whose contributions were recorded in the Shut Out Report or those who related their personal experiences through the consultation process.

What the paper has attempted to do in part is to cast a critical eye over the interpretation given to the contributions and challenges their translation into emotive generalisations. An approach that has lead to essentially *cutting out* those whose needs go well beyond what community inclusion might offer. The report as such ignores the realities that underpin direct care and support. By association this Response has also sought to highlight what can only be described as a passing reference to families in the report. The significant role of families and their contribution in propping-up the broken disability service system has been largely ignored.

Given the report purports to be a major plank in developing a National Disability Strategy, this Response paper also seeks to demonstrate how the proposed initiatives identified in the report are either outdated or lack hard edged detail. Most of all however, this paper proposes seven must do actions if the broken disability system is not only to be fixed, but to be sustained over time.

The Response concludes that if the seven must do actions commencing with an entitlement to services are ignored or are papered-over, the system will remain broken. As such, the failure to fix it must then be as accepted as failure of the NDS and the political will to truly apply the real meaning of rights and choice, and to put into action the UN Convention

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