Submission to Australian Government Productivity Commission
Inquiry into Disability Care and Care
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Personal Background

Age 54
Married (wife Judy) with 3 adult children including a 25 year old daughter with a severe intellectual disability
Employment, Director, Adtrans Group Ltd (ASX ADG) 1986- 2010
Qualifications: Diploma Teaching, Bachelor Education, MAICD

Disability Sector experience

Founder D4D (Dignity 4 Disabled 2004), President 2004-2007
Founder "Disability Speaks" 2008-
Founder Intellectual Disability Association (SA) (IDASA), 2009-
Member Minda Advisory Board 2006-
Director Mc Guiness, McDermott Foundation 2007-

Introduction

Like many parents and carers of a child with a disability for a long time I believed that the government would automatically provide the support and services that our daughter needed because it was the governments duty to do so. Our family was shocked in 2004 when our daughter was completing school to find no day options were available.
Since 2004 I have done a considerable amount of advocacy work and believe I have a broad understanding of the disability sector seen both through the eyes of a businessperson, a carer and an advocate with a broad network of contacts and perspectives.

What I have seen horrifies me! If there is a more dysfunctional sector anywhere in our community it is not apparent to me I would summarise the functionality as follows.

Problems in the disability sector fall into one of four major categories

- The quantum of services available
- The quality of services available
- The flexibility of services available
- The priority of the sector to outside decision makers

There are common conclusions that can be drawn from available data and experience. My observations include

1. The states have not met their obligations under past funding arrangements either in quantum or based on moral criteria (in 2004 then SA Disability Minister Jay Weatherill was questioned on ABC Radio if he had commented privately to disability sector leaders that the problem was there was no votes in disability. The minister denied the allegation despite the rumour being very strong)

2. The Federal Government has not used their power to force the states to meet their agreement obligations. Most recently the Rudd government was elected on a platform that included additional funding for disability services on a state /federal matching model. Not only did the states largely not match the additional funding in a number of instances the states used federal funding as replacement funds for their own contributions

3. The quantum of services available is so manifestly inadequate that effectively no genuine service delivery option or future plan is evident anywhere

4. That demand outstrips supply and the position is deteriorating past critical levels

5. The federal government contribution for services is manifestly inadequate based on capacity to contribute

6. User pays which has become a source of funding across most other community services (with the exclusion of health) is not appropriate due to financial incapacity of most service recipients

7. Massive funding is contributed by the Federal Government notionally as Disability support eg pensions and carers payments and it is questionable if all recipients are genuine or should be eligible.

8. Funding distributed by the Federal Government is done based on equitability not need

9. The disability sector has contributed significantly to the problems by participants understandably largely championing their own personal priorities or philosophies to the detriment of the greater good. the sector offers much complaint but few solutions.

10. The lack of resources has caused a cannibalistic or survival mentality to develop within the sector whereby the need to be first in line within the disability community has become the key priority for likely service recipients achieved at what ever cost

11. This infighting has left gross distortions of the representation with in the disability community and is being accepted as common place. For example the Australian Federation of Disability Organization purports to be the peak body for people with a disability in Australia. By its charter the Federation excludes from its membership access to carers who represent people with Intellectual Disability. How can you be a peak body when the largest group of consumers (over 45% of NDA clients have an Intellectual Disability) are unrepresented

12. Too many within the disability sector define themselves personally by historical power bases and this stifles progress and policy and service development. For example the loftily named National Council on Intellectual Disability (NCID) has eight members. The SA chapter SACID can not fill its board, can not generate funding, has few active members and is run by 3-4 people who under the guise of their lofty title and long standing national accreditation with NCID purport to make significant representation. To highlight the disfunctionality of NCID only 5 of the 8 members have a website! and NCID membership appears to be for life regardless of contribution or out come.

13. The decision makers in failing to deliver services due to inadequate resources have moved to a model whereby government organizations and instrumentalities are more concerned with presenting a politically correct face. Having conferences, meetings, consultations and phone ins is seen as doing something, whilst minimizing political damage control which is the outcome most important to them.

14. Clients begging and fighting for even the tiniest bit of service support have been trained by the system to be grateful for what ever crumbs they receive.

15. Many clients and potential clients are blissfully unaware of the reality of current and future service provisions

16. The disability community is rarely asked what services it requires as such questioning may raise expectations

17. Many in the disability sector when asked about service delivery reply with holistic and philosophical responses that lack commonsense and commercial reality. Why the disability sector would expect pure and perfect service delivery when the rest of the community eg schools, hospitals and public transport operate on a basis of outcome against financial compromise is incongruent.

18. Innovation is stifled in the disability community and historically the disability community is not asked to come up with cost effective or family managed situations that may stretch funding further.

19. State governments have failed to acknowledge or continue to ignore that NGOs, people with a disability, families and carers can deliver services cheaper than they can. While businesses have largely become more specialised and subcontracted as much of their support as possible to experts eg financing, It , transport ....for some reason the State Governments largely believe they have a duty to be disability service providers

20. Much of Disability Policy has been strangely based on research and academics. Even today people are forced against their will into housing models and other disability services because academic theory suggests it is appropriate. This gives rise to the extraordinary situation where the general community has flocked in the last decade to high rise and inner city congrgate living, largely based around lifestyle options and transport and often with a coastal theme yet most state governments still are forcing people with a disability to live in the suburbs under the guise of community living.

21. History shows using Academic research as a basis of social policy has been spectacularly unsuccessful across a wide range of social and community issues. It is not long ago that Indigenous children were routinely removed from their parents, that women were considered weak and inferior, that homsexuals were electrocuted as part of a reprogramming policy and lefthanded school children were caned for their stupidity and stubbornness. History will mark very poorly the disability leaders, politicians and academics who believed they has an ultralistic right to tell others how they should live their life. Horrificly organizations like SACID in SA still today have as part of their charter today. it is little wonder they ahve few supporters.

The states have not met their obligations under past funding arrangements either in quantum or based on moral criteria
The rights of people with a disability to adequate services must be legislated commesurate with the rights the general community has for other services including healthcare, education and social supports. A significant strengthening of the equal opportunity act may address this issue.

The Federal Government has not used their power to force the states to meet their agreement obligations.
The Federal Government must use its power to ensure the states fully meet their liabilities under NDA or what ever new agrreement is in force. Given the systematic and chronic underfunding that states have operated under a catch up contribution is esential from the states and guaranteed future state committemnt should be legislated
As an example, the 2010 ROGS Report shows there is nothing pretend about the crisis in SA. The Australian Productivity Commission report (Table 14A.5) shows in 2004-2005 Qld spent $369.3 mill on disability services and SA $228.0 mill. Both states have approx 20,000 NDA clients. By 2008-2009 Qld had jumped too $598.0 up $230.0 mill or 62.2%. SA over five years had gone to $238.3 mill up $10.3 mill or 4.5%. Both CSTDA and NDA required state govt responsibility being met. This is not the case in SA**.**

The quantum of services available is so manifestly inadequate that effectively no genuine service delivery plan is evident anywhere
Approx $5.4 Billion dollars per annum is spent by the state and federal governments under the NDA agreement at present. Using SA unmet need data published annually by the SA government the figures suggest an additional $3.0-3.5 billion dollars per annum would be needed to address the unmet need waiting lists that have built up over 20 years with 7-8%

real growth in future funding per annum to address inflation and increasing demand. The ROGS Report suggests as little as 4% of need is being met.

The federal government contribution for services is inadequate based on capacity to contribute.
Their is clearly a need for the federal government to increase or match the state government funding for services. State responsibility currently includes by far and away the most expensive service accommodation. An alternative would be for the Federal Government to take responsibility for disability accommodation services. A Federal solution would appear a desireable and the only likely outcome.

User pays which has become a source of funding across most other community services (with the exclusion of health) is not appropriate due to financial incapacity of most service recipients.
This is unlikely to change and undesireable but some services could be mean tested based on the consumer but not the carer/ family as is the case now.

Funding is contributed by the Federal Government notionally as Disability support. The implementation of a grading of need with appropriate support is essential. In 2006 SA developed a hierachial ranking system Cat 1-5 for all clients awaiting services. A mother of a child with mild asthma cannot expect to recieve the same carers support as a mother to a child with spastic quadraplegia. Too much of the Federal Funding that is notionally distributed as disability support does not have adequate priority and benchmarks attached as is seen by many as open to abuse by both recipients and government agencies hiding other community problems.

Funding distributed by the Federal Government is done based on equitability not need
Any future plan must distribute supports based on a prioity of need . It could be argued that the current system is little more than a vote influencing approach with small cheques delivered to millions of recipients while clients with high needs are ignored.

The disability sector has contributed significantly to the problems by participants largely championing their own personal priorites or philosphies. While this is no doubt true, it is impossible to blame the disability sector for this situation given their high levels of desperation and the fact they have been ignored and their goodwill taken advantage of by governments for decades. The government needs to ensure that the vocal minority do not dictate disability policy as often has happened in the past. A good example currently is self managed funding. Just like many in the community do not want to take responsibility for home schooling and just want the government to do its job and deliver quality education options the vast majority of people in the disability sector are unlikely to want self managed funding. There remains significant confusion within the disability community between person centred planning and self managed funding. Overseas evidence suggests only about 10-15% of people with a disability will take up SFM if it is freely available. The reasons for ignoring SFM include people with Intellectual disability would need some one to mange their finances so the responsibility transfers to some one else. This responsibility does not address the issue long term supervision and care issue or "what happens when I die which troubles most carers"as the person managing the funding may become incapable and then the person with an Intellectual disability is comprimised. Many people are now looking at SMF not because they want it but because they believe a modicum of additional services may come there way or it may advance them on a priority list.SMF is not a magic bullet or the panacea for the disability sector but rather one of a plethoria of choices that should be readily available but it is not always being being promoted in that fashion by advocates and may not be embraced by government for teh right reasons.SMF is however an essential option that must be offered as part of a broad range of disability service options.

The lack of resources has caused a cannabilistic or survival mentality to develop within the sector;
There is widespread evidence to support this position and many particularly with Intellectual disability feel they are unrepresented and not a priority. Commonly refereed to as wheelies

versus carers the long term divide that exists in the disability sector is destructive. The very different range of needs that clients have, are regularly not catered for in proposed solutions. While for some independance is the benchmark for others social networks, safety, secuirty and stimulation are essential This divide has been established by campaigns that include slogans like "not about me without me" and the establishment of consumer advisory groups in SA like DANSA has been a contributor too this unhealthy division. It is impossible to understand why governents have not ensured equitability in representation.

There is widespread acknowledgment today by people with depth of understanding of people with intellectual disability that people with an intellectual disability are in the main highly social beings who thrive on and delight in the company of people including those like themselves. Most people with an intellectual disability do not enjoy a rewarding career or a family of their own. It therefore follows that the other cornerstone of our own lives - the social network- assumes even greater importance in their lives than in the lives of their non-disabled peers or people with other forms of disability whos ability to communicate is less restricted . While the " disability experts" previously demanded integration and inclusion in the general community, they disregarded the right and need of PWID to make social networks within their own community and the experts espoused a system that strangely none in the wider general community would accept in being told where and how to live. In 2009 SA as part of its Strategic Plan overhaul moved to a strategy that includes the provision of a range of accommodation choices. SA leads the nation in this area.

There is nothing "Dickensen" about the fascilities that are being developed for the wider community. Developers and operators are displaying extrordinary innovation in both the physical facility and the social and community programs they offer to attract more and more discerning clients . Pools ,gyms and bars have been supplemented by theatres, community gardens, rooftop terraces, community events and full time community directors plus of course medical and crisis supports. They create communities within buildings and fascilities while at the same time maximizing the opportunity for residents to interact with the wider community at their leisure.

While lagging in disability support S.A. has already done extremely well with innovative projects for homeless people which must be considered a guide as an option of choice for disability accommodation. In providing high demand inner city living at Common Ground (60 units) and The Terrace on South Tce (100 units) . These lifestyle villages are super popular with the residents.

The other major plus that is embraced by the wider community is that not only is there life style benefits in congragate living but there is also significant financial synergy that the disability community needs to investigate, consider and possibly embrace

This infighting has left gross distortions of the representation with in the disability community as being accepted as common place. In SA DSA funds the Physical Disability Council for some $14k per annum and financially supports DANSA a consumer group for people largely with non intellectual disability. DSA provides no financial support for Intellectual disability. There is no question the system that has developed over time is lopsided, unrepresentative and biased and people who are unable to speak for them selves eg those with an Intellectual Disability are disempowered.

Too many within the disability sector define themselves personally by historical power bases and this stifles progress and policy and service development. The answer is to consult with consumers and consumer groups that meet appropriate modern benchmarks. That the Federal govt would fund and seek advise from an "old boys club" with little more than cronyism as its base is appalling. History must not be the basis of communication but a better set of benchmarks established that ensure the advisory channels are truly reflective of consumers choices. The establishment of a National Disability Council, with a balanced charter and Federal funding at both State and National level is essential and urgent. This must be a cornerstone of future development

The decision makers in failing to deliver services due to inadequate resources have moved to a model of positive political outcomes.
Disability services are now driven by little more than politicians playing for political outcomes or to avoid political retribution. The ROGS support suggests that states have given up on any attempt to meet their obligations.

Clients begging and fighting for even the tiniest bit of service support have been trained by the system to be grateful for what ever crumbs they recieve
Their is a groundswell of demand for change in this area. People are dying in the disability sector often harmed by parents and carers who cannot cope. Parents are not killing their children because there is a lengthy delay to have their tonsils out in the health system, because the "My School" website score for their area is low or their super fund is sparse! This grateful culture is crumbling as the scope of the disaster is unfolding and will continue to do so..

The disability community is rarely asked what services it requires as such questioning may raise expectations
In my business we constantly ask our clients and potential clients what they need, what they want and how they want it delivered. My ability to consult widely and deliver a menu of service options to suit my business clients both current and future is the guarantee of future success for our business (and my career)) Our daughter has been a client of disability SA for 21 years (age 25 now) and we have never been asked regularly or comprehensively what we require and when and how! Person Centred Planning is a must for resolution of this issue. We have been told on a number of occassions that we are not asked as they do not want the impression created by DSA that services may be forthcoming

Many in the disability sector when asked reply with holistic and philosophical responses that lack commonsense and commercial reality.
When you have next to nothing people tend to dream. The disability sector is no different and they must be educated that such utopian outcomes will not happen. People within the disability sector must however be guaranteed that commercial outcomes relative to broad community standards in other service areas eg health and aged care are provided in the disability sector and be given Legal support when

Historically the disbility community is not asked to come up with cost effective or family manged situations that may stretch funding further. This seems strange as we all run our own lives by stretching and shaping our incomes to our needs and wants. SA as part of the change in strategic planning as DSA embraces the concept of choice and is making early steps in this direction and should be congratulated.Clearly there is significant upside both financially, in service outcomes and community integration if the community can be empowered either as part of SMF or other innovative programs to explore service model options that meet basic criteria like the acknowledged benefits of the accommodation of intellectually disabled clients in smaller living facilities while giving

- a person centred planning approach to enhancing the quality of life for such clients
- community management of the program
- the essential involvement in community interraction for clients
- an enhanced recurrent funding model to maximise accommodated client numbers from limited govt resources
- the professional support of a professional NGO for supply of staff, training, probity and administration support.
- a model able to be duplicated in other settings

- to incorperate best practise eg mixed sex accommodation, community management where ever possible

- maximum social benefits for the clients

This would help overcome the problems of commonly related occurences within the establishment of current small group service delivery facilities including

1. They are expensive to recurrently fund

2. The quality of program out come is not related to bricks and morter or the small group situation

3. There is a wide discrepancy in the quality of outcomes that are delivered from such models

4. A large number of clients and advocates supporting a choice option oppose small group accommodation as they fear isolation and loss of social interaction with peers eg isolated at home

5. They are difficult to manage and supervise for best outcome client centered programs as the dispersal of facilities stretches already stretched Govt/ NGO management programs

6. They often deliver little genuine interaction with the wider community

7. Client mix and appropriate staff allocation is often driven by necessity and not planned or controlled negatively impacting on outcomes

8. Problem resolution is difficult

Recent supporting references include

- Disability Accommodation and Support Framework Report" Victorian Department of Human Services 2008

- Dispersed or Clustered Housing for Disabled Adults, a systemic review Mansell J and Beadle Brown 2008

- Supported Accommodation Services for People with Intellectual Disabilities, Centre for Disability Studies, Ireland Oct 2007

- Our Presence Has Roots, Janet Klees Oct 2005 (Deohaeko Ontario Canada)

- Australia's ratification of the UN Convention on the Rights of Persons with Disabilities, Office of the Public Advocate, Victoria, March 2008ke

State governments have failed to acknowledge that NGOs, people with a disability, families and carers can deliver services cheaper than they can.While businesses have largely become more specialised and subcontracted as much of their support as possible to experts eg financing, It , transport for some reason the State Governments largely believe they have a duty to be disabilitys ervice providers

A model where Disability services are Federally controlled, Regionally managed and locally delivered would appear to be the best outcome. It is difficult on any scale to justify why State Governemnts persist as service managers and service providers as such duplication with the NGO sector is resource diluting. The recent well documented examples where the Federal funding of new school buildings and the benefits obtained by non government schools through autonomy, flexibility and local control reinforce this concept.

Much of Disability Policy has been strangely based on research and academics.

Even today people are forced against their will into housing models and other disability services because academic theory suggests it is appropriate. This gives rise to the extrordinary situation where the general community has flocked in the last decade to high rise and inner city congrgate living, largely based around lifestyle options and transport and often with a coastal theme yet most state governments still are forcing people with a disability to live in the suburbs under the guise of community living.History shows using Academic research as a basis of social policy has been spectacularly unsuccesful across a wide range of social and community issues. It is not long ago that Indigenous children were routinely removed from their parents, that women were considered weak and inferior, that homsexuals were electrocuted as part of a reprogramming policy and lefthanded school children were caned for their stupidity and stubbornness. History will mark very poorly the disability leaders, politicians and academics who believed they has an ultralistic right to tell others how they should live their life.

An extrordinary era that will be seen as a failure is coming to an end. Future policy must enshrine the concept of choice. Person centred planning, an acknowledgement that people who are unable to speak for them selves are entitled ipso facto to an alternate voice and a culture of demand driven service style will deliver a vastly different service landscape very quickly.

The Key Questions of the Issues Paper (May 2010)

The solution proposed with strong similarities that mirrors in many ways the Medicare/ Health approach is fundamentally sound

1. The responsibility for identifying and sorting by priority service recipients at least in the short term should rest with the states. The current State based communication chains if adequately funded and modernised eg database, CRM, online would be realistic. Priority could be established around a common national matrix. Th SA cat 1-5 Matrix is adequate (developed 2006)

2. Clients with the highest needs remain the highest priority. Basing the need on the age of the carer is fundamentally flawed. Such approach lends comparison with business promoting staff on length of service not merit. The establishment of a ranking of need and an acceptance that a base level of attention is urgent is essential when attached to a provision of services

3. The significant urgent expansion of accommodation, respite and in home care are essential. The provision of accommodation system nationally has collpased as stae governments refuse to provide funding

4. Whilst early intervention is desireable in the long term in the short term the focus must be on de stressing the critical areas of the system where life and quality of life are long standing and desperate.

5. Work place support is essential and a plethoria of business incentives are available to be implemented to encourage business support. Ideas similar to workcover and other return to work schemes would be transferrable.

6. State governments should quickly become service managers, not service providers. A whole of life client centred personal plan similar to a medical record would address this issue. State governments should assume responsibility for management of key disability service out comes including case files and plans and monitor service delivery quality. A three way management cycle eg the client of their representative, the service provider and the manager would alleviate inappropriate outcomes. Like Medical services the ultimate decision must resy with the client.

7. Service delivery would be improved by allowing a variety of choices eg block funding for NGOs, SFM, Community Program funding and a menu of other options. The largest wins in cost, timeliness and innovation would be from a community

development approach, particularly if a joint venture arrangement could be struck with a NGO.

8. The federal govt can not abdicate its responsibility to decide how much support people get. Attempts to do so in the past eg CSTDA and NDA have failed. Major social programs have historically been and will continue to be the responsibility of Federal Governments. The irony of the collpase of the national disability support system in line with the implementation of the first CSTDA agreement in the early 1990s can not be ignored.

9. The good aspects of the current syustem appear to largely revolve around relationships people have with service providers and NGOs. By removing the state "middleman" these relationships will be enhanced. Good service providers and NGOs will welcome the concept of SFM and person centred planning as their services will attract more clients.

10. Rural and remote areas must be treated equitably for service support as per health and education.

11. as above see 1 and 2

12. Technology, ID numbers, online log ins. I can buy a $500,000 house without ever leaving my office but cant get both parents listed as decision makers on my daughters disability support payments. THe current system, both state and Federal is a dinosaur and costs a fortune. Placing the funding at the closest point to the end user eg distributing $500 million to NGOs to create Innovative and flexible programs would deliver massive and immediate benfits.

13. Funding is the big one no doubt and requires a multi faceted approach

- The states have been delinquent in their responsibilities and must contribute to a future scheme otherwise they have no interest in management or cost minimization. A fixed percentage of total state budgets eg 2.5% should be legislated as annual contribution for recurrent services

- The Federal Govt should restructure on priority the Disability Pension recipients and Carers allowance based on priority and need, not political outcomes.It is questionable if this funding currently realises real disability service outcomes despite being labelled a disability support fund. AS such the disability title paints a false or misleading picture. There is a clear difference bewteen clients with dependance disability and recipients with other ailments or motivation. For example I am aware of a 62 year old lady who has been on a disability pension for years. She works as a cash for kind in a gymnasium and runs marathons as a hobby. She has a medical certificate for occasional bouts of depression. She recieves the same pension as my daughter who needs 24/7 care and is incapable of any personal support. Abuse or rorting while not politically acknowledged is widespread and commonly known and causes much angst within the disability community given the dire need that exists.

- Like it has done with Foreign aid the federal Govt needs to apply a regulated share of the Federal Budget to Disability services each year

- The concept of an additional community contribution is important. The best way for people to embrace the ideals behind true disability integration is to be a stakeholder. The concept of increasing the GST rate or medicare levy is simple, realistic and marketable to the community.

14 One would imagine a substantial scheme change could take 3-5 years to implement. Clearly there is a massive need for an urgent crisis injection of support (probably in the order of $3.0 billion via the current systemn asap. If that injection was made combing both Federal and State support on a platform of innovation and community involvement there would be little doubt it could serve as a pilot and spring board for long term positive options..

15 I suggest the name National Disability Insurance Scheme is not the most appropriate. If the general community is to both contribute financially and support the resolution of this crisis a name that does not throw up the connotation of " insurance" would be in my opinion more approriate. Succesful programs like Foreign Aide and Medicare paint a differnt brand image and picture that is both positive and more encompassing of the community. An alternate name for this program should be canvassed , researched and promoted that does not include the use in the title of insurance

16 It should be noted that SA has already under the stewardship of our current and previous Minister's made significant progress in restructuring and reshaping the organization of disability service delivery between 2006-2010. Both Ministers Rankine and Weatherill should be congratulated for many changes they have made albeit at a speed less than the disability sectors urgently needs. Regretably the Ministers have not been supported by the Govt with desperately needed additional funding so structural change has not delivered service enhancement yet. Very positive changes made include

- Closing disfuntional govt services delivery units like IDSC
- Compiling a single state based waiting list register
- Implementing a priority sorting matrix based on need
- Appointing non traditional DSA Executives with a charter of consultation and choice rather than crusty academics who believed they knew how services must be delivered
- Consulted widely
- Developing new startegic plans that focus on flexibility and choice
- Developing and rolling out SMF pilot plan as a future service option
- Recognising the clients with Intellectual Disability need equitable representation and different service outcomes (IDASA)
- Working on alternate, cost effective specialist accommodation models eg Kardinya
- Supporting innovative sector restructuring like the Minda proposed redevelopment
- Responded to community pressure and been accessible.

This progress is significant and in many areas leads the nation and should be recognised as such.

17 To suggest the current system nationally is totally hopeless is incorrect It is restoreable with strategic change and appropriate funding.

Thank you for accepting my submission
FINISH