Inquiry into a long-term disability care and support scheme

Submission to the Productivity Commission

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A National Disability Insurance Scheme

"From Charity to Equality"

Executive Summary

In spite of many changes implemented in the disability sector over recent years and decades, inquiries, literature and anecdotal evidence tell us that little has changed. This submission validates this belief and identifies the critical element responsible and that has been a constant for several centuries.

The charity model of disability care has perpetuated inequality, and has denied people with disabilities ownership over their own lives. It started in church institutions and progressed through the social construct of disability, and then under Social Role Valorisation (SRV), which is alive and well today. SRV principles are even enshrined in the Disability Services act.

This submission introduces a radical change in relationships. Power is presently concentrated at the top with funders who delegate some to service providers, who then become the gate keepers and controllers with service users only a spectator. This submission describes a transformational reform where, through devolution of power and the introduction of proven systems, the current top down system can be changed into a system of collaboration, co-production, and empowerment of service users.

At the heart of the proposed new system lies Local Area Coordination, as developed in Western Australia from 1988. Its culture of building respectful and lasting relationships with service users means that Local Area Coordinators facilitate rather than control. Local Area Coordinators also have authority allocate funding to people with disabilities: money they can control themselves. This system of service users controlling their own budgets is based on a British system called 'inControl' which was introduced in 2003. The effect will be that service providers will need to adapt and become part of this symbiotic co-production, and provide services that service users want, rather than take-it-or-leave-it services. The overriding objective is to create an empowering environment that will encourage self actualisation.

A critical part to this plan is a non adversarial conflict resolution system. Proposed is a system with a focus on protecting the vulnerable where, to reduce errors in decisions, the level of proof is lowered proportionally to the power imbalance between the parties

This submission also supports broad eligibility criteria with mental health included, a cross government and whole of life philosophy, MediCare style funding, with the option to adjust rates relevant to cost variations.

Recommendations

1) An interface between people with disabilities and funding providers, based on the West Australian system of Local Area Coordination (LAC)
2) Due regard be given to the need to grow this LAC culture, and to protect it from becoming compromised by prevailing public service cultures
3) Introduction of self directed services, based on the ‘inControl’ system as an option to service users and service providers
4) A symbiotic relationships of co-production between people with disabilities, funders, and service providers, through the devolution of powers, and grounded in LAC and community development principles
5) A non-adversarial complaint system in which protecting the vulnerable is the primary goal,
6) The system be a universal, national, one
7) A broad, whole of government approach
8) A whole of life approach with a seamless interface with early intervention and age care
9) Very broad eligibility criteria, definitely including mental health
10) A MediCare system of funding, with capacity to vary the rate to meet cost variations,
11) Hiring principles throughout with the following values not-negotiable:
    - a sound values base (positive and contemporary attitudes towards people with a disability)
    - understanding of and commitment to the values and charter of local area coordination
    - the ability and willingness to develop and maintain positive and trusting relationships with people with disabilities and their families
12) A high level of training and mentoring to address the unpreparedness for the radical changes being introduced. by service users, service providers, funders and the community at large
13) Due regard for Murphy’s Lament: “Why is there never time to do the job properly, but there is always time to do it twice!”. Getting it right is more important than doing it quickly
14) Legislation. Frequently legislation formalises changes in community thinking, perceptions and beliefs, however there are times where government through legislation must lead. Examples are compulsory seat belt regulation, and the move towards use of solar power. In both cases legislating unchosen change speeded up acceptance and implementation. The NDIS for many is about unchosen change, and that includes key players in the sector. Government leading through strong legislation will ensure quicker acceptance, and hopefully understanding, and shortened time lines for implementation

1. Introduction

Former deputy prime minister Brian Howe is one of a number of influential social policy analysts who believe the time has come for a “paradigm shift” in Australia’s disability services system.[1]

The National Disability Insurance Scheme (NDIS) was a development from the ***“Disability Reform: From Crisis Welfare to a Planned Insurance Model”*** paper by B P Bonyhady and H Sykes, submitted to the 2020 Summit in Canberra in April of 2008. It is now endorsed by more than 150 disability and community services in Australia.

The NDIS, as proposed will be no fault, inclusive, a uniform national system and needs based. It will insure security of resources, and will be the biggest reform in disability funding ever seen in this country.

The Productivity Commission’s (PC) Terms of Reference (ToR) for the inquiry have a strong economic focus, however its ‘Issues’ paper takes a much broader view.

Publicity in the last year or so has given the impression though that the main game is about money. If one of our aims is a universal scheme aiming to make the stream wider so no-one gets left behind on the edges, then money is of course important, however it does not constitute the paradigm shift for which Brian Howe and many others are calling.

The transformational change needed is about relationships and a readjustment of power. The current system of resource management and service delivery is top down, it is hierarchical, feudal, and out of step with today’s thinking and expectations. To meet the needs and expectations of people with disabilities, their relationships with funders and service providers must change. As a community we must embrace a culture where responsibility, authority, and ownership are shared. The key to this is devolution of power, not its relinquishment, but its delegation in a meaningful way.

2. Background

‘Don’t change anything until you thoroughly understand what is there’ said Major General, then Governor General of Australia, Michael Jeffrey[2].

What, with all the changes in the disability sector over the years, decades, and centuries has prevented people with disabilities from owning their own lives? If every life is a question in search of an answer[3], then what stands in the way of people with disabilities answering the question of their own lives? It is not people’s disabilities, but our society that has been the major impediment to inclusion, and it follows that it is us, society that needs to evolve and redefine our relationships.

“Charity maintains poverty” said Mohammad Yunis.[4] From the days of Jane Eyre, Charles Dickens, to this day, disability support has been treated as charity, giving alms to the deserving poor.

Institutions

Australia has been influenced by many of the British institutions, including the institutions that Emily Bronte, Jane Austen, and Charles Dickens chronicled, both church and state. However this system was hierarchical and created a sub-class in a rigidly class conscious society. The ‘beneficiaries’ of this charity welfare were powerless to influence their own lives. It was a system without accountability where power corrupted and led to abuse.

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[1] The struggle for care, Corrigan, S., 270309, The Australian

[2] Margaret Throsby interview, ABC Classic Radio, 260607

[3] Heidegger, M., cited Deegan, P., Recovery as a journey of the heart, 1996

[4] Mohammed Yunis, Founder of the Grameen Bank of Bangladesh, Nobel Peace prize winner, 2006.

These institutions became part of Australia's history for more than 150 years, and little changed since Dickens' time:

> *"Claremont Mental hostel was a custodial institution implying that its residents were dangerous and needed to be kept away from "normal" people in the community. There was no education or stimulation or attempt to enable the residents to move out. It was custodial care of the lowest kind".*
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> Dr Guy Hamilton, former Superintendent Mental Deficiency Division, Health Department (W.A.), 1962 – 1982.[5]

In the fifties parents were advised to put their children with disabilities in institutions and "forget they ever had them".[6]

The Social Construct of Disability

The Industrial Revolution formalised this inequality through the social construct of disability, which made people with disabilities a separate sub class, isolated and marginalised. Those who could not meet skill and productivity standards were declared unfit, and excluded from paid employment (Russell and Malhotra, 2002[7]). The disabled, particularly the intellectually disabled, were considered a social problem. They were excluded from mainstream life and were transferred to institutions, workhouses, asylums and prisons (Ariotti 1999, p. 216)[8]. The social construct of disability contributed to legitimising the institutional system.

When in the nineteen eighties institutions were closed and residents were re-settled in the community many people found that they had moved from institutions into 'institutionettes' and were behind a one metre fence just as isolated from community as they were previously behind a two metre wall. The institutional culture and industrial practices had not changed, and as before, there was no capacity to engage with the community.[9]

Normalisation

In the eighties the social model of disability became all the rage. It purported to address the social and emotional needs of people with disabilities as well as their physical ones: levels three and four in Maslow's Hierarchy of Needs: 'self actualisation', empowerment.

Normalization developed by Neils Bank-Mikkelsen (1980) of Denmark and Bengt Nirje of Sweden in 1969, was introduced in Australia in the eighties when de-institutionalisation was gaining momentum, and became the dominant philosophy.

> *"Making available to all mentally retarded people [sic] patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society."* (Perrin and Nirje 1985:69)[10]

Wolf Wolfensburger developed his version of normalisation in 1972 and called it Social Role Valorisation (SRV)

> *The highest goal of the normalization has recently been clarified to be the establishment, enhancement, or defence of the social role(s) of a person or group, via the enhancement of*

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[5] Hamilton, D., cited Croft, D., When needs go Begging, Disability Services Commission, WA, 2000

[6] Croft, D., When needs go Begging, Disability Services Commission, WA, 2000

[7] Russell, M., Malhotra, R., 2002, cited Wiltshire, D., The Social Construction of Disability, 2004

[8] Ariotti, 1999, p. 216, cited Wiltshire, D., The Social Construction of Disability, 2004

[9] Paton, S., Homan, J., Learning with Amanda, 2004

[10] Perrin and Nirje 1985:69, cited Campbell, F., Social Role Valorisation Theory as discourse: bio-medical transgression or recuperation?, 1998

> *people's social images and personal competencies. It is proposed that normalization be henceforth called "social role valorisation."*[11]

Normalisation or SRV aims to make people who are different appear ‘normal’, not different. It is envisaged that they will be better placed to be respected and accepted in society; however:

> *“… the arbitrary disciplinary process of normalisation [“SRV”] has robbed us all of our difference, our society of its sensitivity to diversity and thus of true tolerance, and our culture of its potential richness, all to serve ultimately the interests of a privileged minority”.* (Branson and Miller 1992)[12]

Normalisation’s culture and practices did not lead to empowerment. They further legitimised the status quo. SRV and Normalisation have proved to be as controlling as the medical model and so, what is referred to as the social model of disability, is in fact no more than a new version of the medical model.

> *“One of the central contradictions of normalisation [“SRV”] is that while it purports to re-value people with disabilities, it is rooted in a hostility to and denial of “differentness””.* (Szivos 1992:126)[13]

“SRV” is seen by many as ‘best practice’, and has significantly influenced the Disability Services Act 1986 (DSA). The legislation emphasised de-institutionalisation by enshrining “SRV” principles into its Objects (s.3) and the Act’s Principles & Objectives. [xx] (Campbell, F., 1998)[14]

2. Business as usual

The feudal, hierarchical, top down, charity model has had a variety of guises but has maintained inequality and marginalisation of disabled people till this day.

This is borne out by the Shut Out[15] report:

- *“56 per cent of submissions received discussed the experience of exclusion and the impact of negative social attitudes on the lives of people with disabilities and their families, friends and carers.*
- *Many submissions said that there is little or no choice in services provided, particularly in regional or remote areas.*
- *Submissions and participants at community consultations said that the system is characterised by a ‘one-size-fits-all’ approach in which there is very little choice or flexibility.*
- *Programs and services are built around organisational and system needs rather than the needs of clients”.*

John Pini, Manager of Disability Services with Uniting Care,[16] observed that when professional people talk about the need for respite, accommodation support, community access et cetera, that's

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[11] Wolfensburger, W., Eric Education Information Centre, 1983 http://www.eric.ed.gov/ERICWebPortal/search/detailmini.jsp?_nfpb=true&_&ERICExtSearch_SearchValue_0=EJ299722&ERICExtSearch_SearchType_0=no&accno=EJ299722 (sighted 070810)

[12] Branson and Miller 1992, cited Campbell, F., Social Role Valorisation Theory as discourse: bio-medical transgression or recuperation?, 1998

[13] Szivos, 1992, cited Campbell, F., Social Role Valorisation Theory as discourse: bio-medical transgression or recuperation?, 1998

[14] Campbell, F., Social Role Valorisation Theory as discourse: bio-medical transgression or recuperation?, 1998

[15] Shut Out, National People with Disabilities and Carer Council, 2009 (p2)

[16] Pini, J., Unicare, at PC hearing Canberra, 130710

all disability speak. That's not someone having a good life! That's segmenting people up into categories so that the funding can be organised in a particular way.

At present all power resides with the funding providers, who then delegate some of this power to service providers, who as ‘contractors’ are accountable to the funding bodies. Service providers become the ‘gate keepers’ in the system. They manage the resources, block funding as well as individual funding, and decide on the type of services they want to deliver. The professionals are at the centre of the process, and the ‘client’ is generally only a token participant in the decision making process.

3. Relationships

The relationship between funders, service providers and people with disabilities and families may be represented by the organisational pyramid with the funder and the power at the top, service providers with delegated power in the middle, and service users – the supposed beneficiaries at the bottom with little or no influence over how their lives will be lived. Funders tend to relate principally to agencies rather than the people served and, hence, these agencies see themselves as the “agents of those they serve”.[17] It is an example of what Hood (1997) refers to as a ‘steering contract state’ where government strives to maintain as much flexibility and control as possible, thus to be at arms length from service provision and to use competitive “contracts as an instrument of discipline or control” over public service providers.[18]

This controlling relationship needs to become one of collaboration, a co-production between funder, service provider, and service user. The three layers of the pyramid must be separated and re-arranged in a triangle, on a common level. This permits respectful relationships that are facilitating and not controlling. Hood states that an empowering contract state develops a co-production relationship between public administrators, non-government service providers and citizens. (Hood, C., 1997)[19]

With the three parties in a relationship of collaboration or co-production it becomes possible to create and grow the sort of environment that may lead to the self actualisation to which Maslow refers.

4. Culture

How well are our present bureaucracies equipped to create an empowering environment? Not very well is the answer. Bureaucracies have adopted Frederick Winslow Taylor’s ‘Principles of Scientific Management’, where management secures a monopoly over knowledge to control each step of the labour process in order to maximise efficiency. The system was designed for efficiency on the production line, but has no place in the community sector, as it places a dead hand on innovation and creativity (Stephen Long, 1999)[20]

Michael Kendrick observed that bureaucracies are becoming more important than the community sector itself, and gradually turning inwards into their own preoccupations, and with a deep disconnection from people with disabilities directly, but also the broader community.[21]

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[17] Kendrick, M., When people matter more than systems, 2000

[18] Hood, C. Which Contract State?, 1997, cited Yeateman, A., Competitive Tendering and Public Values, 1998.

[19] Hood, C. Which Contract State?, 1997, cited Yeateman, A., Competitive Tendering and Public Values, 1998.

[20] Long, S., Taylorism in an IT world, Australian Financial Review, 1999

[21] Kendrick, M., Meeting with Michael Kendrick regarding the development of the new Disability Services Agency in Queensland, 1999

Is it possible to change a controlling culture into an enabling one? Possibly, over time, with strong leadership and focus. However many of the people may not want to change, or may be unable to change. Northcote C. Parkinson observed half a century ago that:

> *"In the presence of wolves sheep are said to form a tight bunch with horns outward and the weakest in the centre. Civil servants do the same. Faced by a common danger, they take up that formation, yielding nothing, denying everything, concealing all."*[22]

Culture change, by any other name, paradigm shift, or transformational reform, is about change, chosen or unchosen, looking at old problems through new eyes. To expect a large group of people to move synchronously in a new direction, with no one out of step is ambitious.

A culture change may be possible, over time, however success is certainly not assured.

Western Australia, rather than attempt such an ambitious change, has side stepped the issue. It has created a new organisation, within, but separate from the Disability Services Commission, and called it Local Area Coordination (LAC) It is staffed by people who already think the 'new' way. Local Area Coordinators have:

- a sound values base (positive and contemporary attitudes towards people with a disability),
- understanding of and commitment to the values and charter of local area coordination, and
- the ability and willingness to develop and maintain positive and trusting relationships with people with disabilities and their families.

Their charter is:

> *To support people with disabilities and their families to identify their own needs, determine their preferred service and control the required resources, to the extent they desire, so that they can pursue their chosen lifestyle.*[23]

One of the most remarkable features of LAC is that it co-exists with a department in spite of a culture that seems totally different, and threatening to the prevailing public service culture, and maintains its integrity. Eddie Bartnik states that the external safeguards are around government support (both Government and Opposition) including Board, Corporate Executive and other agency programs. A sort of "political safeguard", in addition to internal safeguards within the program.[24]

LAC has developed and grown a culture and practice framework that may be described as a generalist or eclectic approach. It exhibits elements of individual co-ordination, personal advocacy, family support, community development and direct funding. The unique quality, and much of the advantage, of LAC derives from the mixing and blending of activities and approaches of each of these human service orientations as well as the intentional design of an ongoing personal relationship.[25]

It has been a widespread belief that individualised funding, where people with disabilities and families control their own budgets, is the holy grail in disability reform. In 2000 Prof Angus Buchanan conducted a research project in Western Australia that aimed to determine whether people with individual funding were more empowered than those without. He was unable to conclusively answer this question as the empowerment levels of people with and without funding were found to be equally high. Buchanan says that it is very likely that the reason for the similar profiles in empowerment across people with and without funding relates to the type and nature of supports that are provided

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[22] Parkinson, C.N., The Law and the Profits, 1960

[23] Grimsley, A., Background Paper, Department of Families, Youth and Community Care, Queensland, 1999.

[24] Bartnik, E., email to author, 250710

[25] Bartnick, E., Chalmers, R., It's about more than the money, Local Area Coordination Supporting People with Disabilities, 'Co-Production and Personalisation in Social Care', 2007

to all the families of people with disabilities. A primary support service accessed by all families in this study is Local Area Coordination. It would appear that the influence of a contemporary service delivery framework, such as Local Area Coordination has the capacity to facilitate the empowerment of all parents and carers regardless of their support needs.[26]

Although the money is important, the co-production between parties in the LAC framework appears to be critical. Co-production in this context describes a particular approach to partnership between people who rely on social services and the people and agencies who provide those services.[27]

5. Self Directed Services

Self directed services are a simple yet transformational approach to public services, which allocate people budgets so they can shape, with the advice of professionals and peers, the support they need. 'inControl' introduced in Britain in 2003, seems to be the most comprehensive, and most studied and reported on system.

Demos[28] in a recent study: 'Making it personal'[29] states that:

> *"Personal Budgets and self directed services mobilise the intelligence of thousands of people to get better outcomes for themselves and more value for public money"*

As an independent and impartial 'think tank' Demos is the preferred source on the 'inControl' system – rather than 'inControl' itself – and gives a very substantial evaluation of this self directed service, as it is current in Britain. For that reason it is used as a main source in this paper.

The shift to a self directed service is transformational for people with disabilities, and Demos identifies five major paradigm shifts. Where traditional approaches put professionals at the centre of the process, the participative approach puts the individual in charge. The result is that:

- By participating in planning and commissioning the services that support them, service users said they became less isolated, depressed, dependent and more optimistic, energetic and confident.
- relationships with professionals change. Professionals become more like advisers, counsellors and brokers, guiding people to make better choices for themselves.
- where traditional services rely on the skills and knowledge of professionals, the participative approach adds a diversity of knowledge from users, families, peers and friends.
- service providers have to adjust to user demand and shift from a mass, centralised form of provision, towards more networked and personalised services. This is a huge challenge for service providers.
- With the shift in power towards users and away from professionals come responsibilities for users like assessing and managing risks and to account for how resources are used. Users generally welcome these responsibilities.

The Process

> *'in Control' allocates resources to people up front so they can plan how to use them. When people apply for support they are very quickly given an assessment of the resources they would have available to buy support. Many applicants self-assess their need using a simple points system. People draw up a self-directed support plan with advice from professionals, peers, family and friends. In other cases the plan emerges through informal discussion with a spouse. Once the plan is approved by the authority, usually a swift process, the indicative*

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[26] Buchanan, A., The Predictors Of Empowerment For Parents And Carers Of People With Intellectual Disabilities Within The Direct Consumer Funding Model, 2007

[27] Hunter, S., Ritchie, P., 'Co-Production and Personalisation in Social Care', 2007

[28] Demos – 'the think tank for everyday democracy', www.Demos.co.uk

[29] Leadbeater, C., et al, Making it Personal, Demos,2008

> *budget becomes real, the money flows to the individual and then on to the service provider of their choice.*
>
> *'in Control' encourages people to revise their plans as they learn what works best for them or as their circumstances change.*[30]

In the NDIS, adopting the Local Area Coordination approach to relationships, the LAC, representing the funder, would have a major advisory and governance role. The LAC must ensure that a support plan is not a wish list, and that it meets government policy objectives to keep a person healthy, safe and well.

Managing the money

> *Many people choose to have the money transferred into their bank account so they can use it to pay for support services as they need them and purchase equipment. People who do not feel confident managing money can appoint a representative, such as another family member, a broker or a local authority care manager to manage the money for them.*[31]

Risk

> *People with personal budgets do not take undue risks; often the care packages they design are lower risk than traditional services; there is more risk sharing between people and professionals; checks and balances can be designed into the system to eliminate undue risks.*[32]

Where government and many organisations tend to be risk averse, individuals are more likely to manage risk.

Fraud

> *As yet there is no evidence fraud is a serious problem with personal budgets in social care. People are determined to get the most out of their money to improve their quality of life. Family members generally work hard to get the best deal for their family.*
>
> *Local authorities can minimise the risks of fraud by putting in place light-touch monitoring and auditing systems to check that a service user's needs are genuine and that their support plan is meeting those needs.*[33]

Because of their close relationships with service users, Local Area Coordinators would be best placed to fulfil that role in the NDIS.

Inappropriate uses of public money

> *Another common worry is that people will use their personal budgets to commission inappropriate services. Usually the only restriction placed on a personal budget is that it should be spent on services that are legal, contribute to meeting the goals of the person's support plan and keep them safe and well. Cases where people spend their money rashly or unwisely are extremely rare. Studies of patients involved in decision-making over budgets for long-term health needs, for example, found they make far fewer unreasonable or irrational demands than clinicians fear; one study showed that patients often prefer more conservative and cheaper treatment than the doctors recommend.*[34]

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[30] Leadbeater, C., et al, Making it Personal, Demos,2008

[31] Leadbeater, C., et al, Making it Personal, Demos,2008

[32] Leadbeater, C., et al, Making it Personal, Demos,2008

[33] Leadbeater, C., et al, Making it Personal, Demos,2008

[34] Coutler, A., The anonymous patient: Ending paternalism in health care, London, the Nuffield Trust, 2002, cited Leadbeater, C., Making it personal, Demos, 2008

Is it bad for equity?

> *This worry is misplaced. First, it implies that the current system treats people in a fair and consistent way. Yet often there is no consistent relationship between a person's needs and the resources spent on them: indeed often the relationship is unfathomable.*[35]

Will it work in rural and remote areas?

The Demos paper makes some comment on rural services in Britain, very different from the Australian scene, and then quotes:

> *In Western Australia, local area coordinators were introduced to respond to the needs of isolated rural communities.*[36] *Coordinators help people find the support they need in their locality rather than having to travel long distances to centralised provision.*

People who do not want choice

Self directed funding is about people having choices: to choose not to join, but stay with traditional services, is one of them. However:

> *Even people who decided to stick with traditional in-house services felt more in control of their lives because they had been through the process of thinking through what they needed and what their options were, and*
>
> *Evidence from similar schemes abroad suggests that people using personal budgets gradually move away from traditional services and become more creative in designing their care.*[37]

inControl – Seven Steps

In a recent Barnsley Council report[38] the process of self directed services is broken down into seven steps. This process will seamlessly fit in with the LAC system as practiced in WA, and could look something like this:

1. **Money –** Through a simple self-assessment questionnaire people know early how much money will be available to them.
2. **Making a support plan –** *'Where do I want to be in life?'* An assets focused approach, rather than the deficits focused medical model of disability. This is a 'co-production' where the person with disabilities leads, and the LAC, and other stakeholders facilitate the process. As needs are not just physical but also social and emotional the plan by its nature must encourage flexibility and innovation, and manage risk and ambiguity.
3. **Agreeing the plan –** once made a higher authority than the LAC has to agree that the plan is 'appropriate', meets guidelines and that risks can be managed.
4. **Organising the money –** is about how and by whom the money is managed.
5. **Organising the support –** or bringing the support plan to reality. Shopping for services, specific or generic, equipment, where the LAC, family and other stakeholders may advise and facilitate.
6. **Living life –** enjoying the benefits of a well designed well executed support plan.
7. **Seeing how it works –** accounting for moneys spent through the LAC, and evaluating and adjusting the plan to make it work better.

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[35] Poll et al, a report on inControll's first phase, 2003-2005, cited Leadbeater, C., et al, Making it personal, Demos 2008

[36] www.disability.wa.gov.au

[37] Leadbeater, C., et al, Making it personal, Demos 2008

[38] http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=1448&cc=GB (sighted 030810)

Evaluations:

> *Professor Chris Hatton of Lancaster University has analysed data from 196 people who are self-directing the support they get in 17 local authorities. This is the largest collection of data of its type so far, and offers a snapshot of the impact personal budgets have on people's lives. Professor Hatton's evaluation shows that most people using self-directed support believe it makes a positive difference to many aspects of their lives, whether they are young adults with learning disabilities or frail elderly people who are largely housebound. Only a small minority, about 5 per cent, feel their lives have got worse in any regard and the majority believe the quality of their lives has improved: they have more choice and control, see friends and engage in their communities more, have a greater sense of dignity, and enjoy better health.* Demos, Making it personal'.[39]

In 2005 the British Department of Health commissioned researchers at the University of Kent to evaluate a pilot project of personal budgets in 13 locations. The researchers reported their findings in 'Do Individual Budgets work, and at what price?'[40]

Carmel Marshall, Diocesan Planning and Development Manager at Centacare Rockhampton, scrutinised the report:

> *- The study was a comparison of 2 sets of people - one group which remained under conventional care arrangements, and a second group that was provided care through individual budget (IB) arrangements.*
>
> *- While a range of different models of dispersing funds were used among those under IB arrangements, the common element was that the recipient decided where the resources were directed*
>
> *- The comparison groups were broken down into: people with physical disability; older people; people with learning disability; mental health working age adults*
>
> *- The assessment was conducted 6 months after the introduction of the pilot IBs, and for some participants rollout had not been immediate, therefore the arrangements were in place for significantly less than 6 months at the time of the assessment*
>
> *- For people with a physical disability (particularly young people) and people with mental health issues, the results pointed to an increase in quality of life. For both of these groups, there was also reported an increase in feeling of "being in control".*
>
> *- For people with a learning disability, the impact of the slow rollout meant that the results for this group were not reliable.*
>
> *- Generally, better social outcomes were seen for people whose IB plans had been in place for a longer period.*
>
> *- The research shows little difference in the cost of the 2 styles of funding i.e. introducing IBs was cost neutral, although it does caution that this doesn't take into account costs associated with developing individual support plans and the loss of economies of scale that are delivered by bulk service delivery.*
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> *The results of the work go some way to supporting the individual funding model being proposed here.* (Marshall, C., 2010)[41]

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[39] Leadbeater, C., et al, Making it personal, Demos 2008

[40] Jones, K., et al, Do Individual Budgets Work and at What Price?, 2009 http://www.crfr.ac.uk/spa2009/Jones%20K,%20Netten%20A,%20Fernandez%20J-L,%20Knapp%20M,%20Challis%20D,%20Glendinning%20C%20et%20al%20-%20Do%20Individual%20Budgets%20work%20and%20at%20what%20price.pdf

[41] Marshall, C., email to the author on 010810

It seems somewhat ‘courageous’ to report on a pilot after six months in which time many support plans particularly for people with an intellectual disability had not even been finalised. Two years may be more realistic to bed down such radical changes.

6. Resources

A number of cost evaluations are cited in the Demos paper, and also in the ‘Do Individual Budgets Work and at What Price?’[42] study. The general opinion seems to be that self directed services are at worst cost neutral, at best show savings of up to 35%, with average savings of around 10-20%.

A major weakness in the British system of self directed services is that it is administered and funded by local authorities. This makes it uneven and inconsistent. The NDIS - proposed as a national universal system - should be consistent throughout the country.

Another weakness in the British system has been that in times of tight budgets Local Authorities have tightened selection criteria, as a means of ‘saving money’. It is of great importance that eligibility criteria are broad and that mental health should be included. It is a genuine disability, even if it may be episodic rather than continuous, but also as John Pini observes, it is frequently one disability in a dual diagnosis:

> *“I would try and have a scheme as broad as possible, so I'd be saying, yes, mental health should be in, but you then may have some layers and grades within that. I think one of the confronting things for me is when I talk to some of my colleagues in Queensland and we talk about people with intellectual disability, they are able to demonstrate that a very significant number of them have a mental health issue as well. A significant number have depression because of the really crap life that they've had to experience. Now, that seems a reasonable response to their very ordinary life, so I'd be saying mental health should definitely be in”.*[43]

If a trusting and credible relationship between people with disabilities and funders is a primary objective then it is critical that resources are adequate so reasonable requests to meet physical, social and emotional needs do not have to be refused. There are many examples in the past of national and state governments instituting social reforms as a cost saving measure rather than their stated objectives of serving ‘the public good’. If the proposed NDIS is funded on a ‘user pay’ basis, like MediCare, the temptation to penny-pinch may be more readily resisted than if the scheme is funded from the public purse.

The Medicare system has strongly resonated with Australians since its introduction in 1983. Although a new tax, it was accepted as it was narrowly focused on giving all Australians a ‘fair go’. It is not unreasonable to assume that an NDIS funded in a similar manner will also have significant popular support.

To ensure adequacy of resources it may be desirable to link a NDIS levy to the CPI, rate of inflation, bank interest rates or GDP variations.

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[42] Jones, K., et al, Do Individual Budgets Work and at What Price?, 2009 http://www.crfr.ac.uk/spa2009/Jones%20K,%20Netten%20A,%20Fernandez%20J-L,%20Knapp%20M,%20Challis%20D,%20Glendinning%20C%20et%20al%20-%20Do%20Individual%20Budgets%20work%20and%20at%20what%20price.pdf (sighted 150710)

[43] Pini, J., UniCare presentation to PC, Canberra, 130710

7. Service providers

> *"It is not the strongest of the species that survives, nor the most intelligent: it is the one most adaptable to change."* Charles Darwin

If service providers become the third leg on a LAC and inControl based service delivery platform, they too will have to adapt. Services will need to break through levels one and two of Maslow's Hierarchy of Needs in the medical model of service delivery and reach for levels three and four, to be able to meet clients' social and emotional needs as well as the physical ones.

Fundamental to both LAC and inControl is the creation of an empowering environment around the person with a disability and family with self actualisation as its objective. Service providers need to adapt if they are to be part of this symbiotic relationship.

This required change does not just affect people on the ground at the coal face. The entire organisation from the management committee at the strategic level, through the CEO to client interface needs to be pickled in it. From Taylor's[44] top down system where all knowledge and wisdom is deemed to be held by a few, all stake holders, including clients, must share ownership, authority and responsibility. As previously remarked, this may not be easy, and may take time, however not to do so may well lead to irrelevance.

> *'The transfer of power and control over funding and support to disabled people has significant implications for providers of support. In a support market driven for the first time by disabled people, co-production may well become a pre-requisite for those who are looking for customer-oriented providers. Those providers that continue to design services on a take-it-or-leave-it basis may find themselves without a role in the future system'.*[45]

The authors of a 2008 study of the impact of personal budgets on service providers[46] when looking at the overseas experience observed that when service providers offered self directed services as an additional option to their existing services there was a loss of existing services, but other opportunities presented themselves.

- In one area, a local authority-funded drama group was being closed down but the provider felt that IB holders would want to continue using it - and use their budgets to fund it - and so decided to continue running it themselves.
- Another provider fostered close links with the local Learning and Skills Council to develop an educationally-focused service involving local colleges.
- One commissioner reported a new culturally sensitive care service being developed in response to the demands of IB holders in their area.
- A provider had started to establish links with telecare and meals-on-wheels organisations, with a view to sub-contracting parts of potential IB packages to these partner organisations.

Some service providers also now offer administrative services to people with individual budgets, which they can do at low cost as the infrastructure is already in place.[47]

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[44] Long, S., Taylorism in an IT world, Australian Financial Review, 0899

[45] Poll, C., KeyRing Living Support Networks and Neighbourhood Networks, in 'Co-Production and Personalisation in Social Care', 2007

[46] Wilberforce, M., et al, The impact of personal budgets on social care providers: perspectives from the Individual Budget pilots, 2008

[47] Wilberforce, M., et al, The impact of personal budgets on social care providers: perspectives from the Individual Budget pilots, 2008

Reading the Wilberforce[48] report gives a strong sense that 'something is missing'. The Demos study, inControl, Local Area Coordination and UniCare have a great deal to say about relationships, collaboration, co-production, and partnerships, and that these are more critical than the money in self directed service systems, confirmed by Buchanan[49]. The only relevant comment in the 'Impact of personal budgets on social care providers' evaluation was that "New support brokers would assist users in thinking creatively about what services would meet their needs, and in accessing information to help implement their plans (Cabinet Office, 2005; DH, 2005; DH, 2006)". Does that indicate 'business as usual' with social workers acting as the risk managers, gate keepers and controllers?

8. Viability

Susan Helyar, the national director of Uniting Care Australia,[50] made the point that there is a need for two levels of funding, base funding to ensure service provider viability, and individualised funding so people with disabilities can go shopping for services. If people however vote with their feet and leave service providers that can not or will not provide the services they want, then they become irrelevant and base funding will put them on a life support system that is difficult to defend or sustain.

9. Co-Production.

John Pini (UniCare) said that in his experience there is a history across states of pushing people across the boundary, "It's your problem and not mine." If you then sort of reconceptualise things and say it's about providing something for this person and drawing the people from mental health, drawing the good medicos and get someone a well-rounded service, that ends up costing you less because they get a response in a timely manner.[51]

Ms Helyar (UniCare) remarked on provision of funding where there is no infrastructure through which to spend the money. About what's happening with the roll-out of the specific autism funding, whereby it's all very well to have individualised funding but if there's no infrastructure through which to spend the funding, you're kind of stuffed anyway.[52]

All this points to a serious disconnect between departments and services, all narrowly focused on a narrow area of interest. Empirically anyone who has attempted to navigate the 'system' will have experienced this. LAC offers the service of experienced navigators, however that is only a band aid solution.

Two steps forward:

- In Queensland a compact is now in place between the community services sector and relevant departments. Also in Queensland a number of departments that address individual and community social needs have been combined into the Department of Communities (DoC), - unfortunately Health was not included - recognising that individual and community needs cross departmental boundaries.
- In Central Queensland, through an initiative by the Queensland Alliance and Centacare, The Rockhampton Mental Health Interagency Community of Practice collaboration was initiated. More than 45 people from 4 government agencies and 16 not for profit organisations are participating, and there is a further flow on effect through the dissemination of meeting

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[48] Wilberforce, M., et al, The impact of personal budgets on social care providers: perspectives from the Individual Budget pilots, 2008

[49] Buchanan, A., The Predictors Of Empowerment For Parents And Carers Of People With Intellectual Disabilities Within The Direct Consumer Funding Model, 2007

[50] Helyar, S., Unicare, at PC hearing Canberra, 130710

[51] Pini, J., Unicare, at PC hearing Canberra, 130710

[52] Helyar, S., Unicare, at PC hearing Canberra, 130710

> information to the broader sector, by bulk email. Participating departments include Community Services, Disability, Housing, Health, Police and Corrective Services.
>
> The Community of Practice approach provides an ever evolving action learning framework through scenario discussion and feedback, that can help equip those involved to meet complex client needs well into the future.[53]

Addressing ‘whole of person’ needs as well as ‘whole of life needs’ is an important part of giving a fragmented sector a single focus: the people it aims to serve.

For whole of life, there needs to be vertical integration/compatibility of systems from early intervention to aged care. Again, to have a single focus on people’s whole of life journey.

10. Infrastructure

Infrastructure is not about real estate and buildings, it is about people. The people speaking for UniCare at the Canberra hearing were very clear on that:

Susan Helyar: Infrastructure in social services is primarily people with a skill set that can evolve over time as our knowledge and the evidence builds around what's effective ways of working with people, and particularly in these areas, it's changing all the time, that evidence of what's good to do. We're starting to build a strong evidence base for the kinds of workforce skills that are needed and that's a fundamental infrastructure that can't be easily funded through an individualised funding arrangement.

I guess the other thing is that the market in social services is different to the market for milk and the responsiveness of the market to change and to shifts in demand are different, so there's long lead times. Particularly if you think about the aged care system, there's 25-year-old infrastructure that needs substantial change but the time frame for shifting that infrastructure is long and older people don't have a long time in their life to wait, you know. So I think the way the market operates is very different in the social services field and that needs to be taken into account.[54]

John Pini said: I was interested in your conversation with Carers Australia about the workforce issues as well because that's critical for us. When the carer was talking about cert III and cert IV - basically don't care what they have - I really agree with her because I can train someone with a cert III or cert IV, a psych, a nurse, a social worker, but what I can't get is the 10 years' or the 20 years' or the 40 years' experience of your son or daughter and the knowledge that you've built up over that time, so regardless of what I bring in to your house, there needs to be some of that exchange, otherwise it's just an array of people coming in and out. It doesn't have a meaning to the relationship that's in there.[55]

Rhonda Held (UniCare) commented that the other thing about workforce is that it isn't just skill sets, it's actually mind-sets as well and there's still a strong residual institutional mind-set amongst the workforce which, if you're talking about individualised community-inclusive recovery based kinds of programs, it takes a change in thinking.[56]

Much has been said about ‘relationships’ in this narrative. Unfortunately because of uncertainty about what it means, many organisations are reluctant or have forbidden support workers to establish relationships with their clients. For every two people there seem to be at least three interpretations of the meaning of “relationships”! There is a clear difference between personal and professional relationships, but there are also many common elements that may lead to a professional relationship

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[53] Paton, S., Homer, V., Rockhampton Mental Health Interagency Community Of Practice, 2000

[54] Helyar, S., Unicare, at PC hearing Canberra, 130710

[55] Pini, J., Unicare, at PC hearing Canberra, 130710

[56] Held, R., Unicare, at PC hearing Canberra, 130710

being meaningful, respectful and beneficial to both worker and service user. Bramston Training and Consultancy has published an excellent guide, which defines freedoms as well as boundaries.[57]

11. Protecting the vulnerable

No matter how far reaching the reforms, no matter the dedication and commitment of government, funders and service providers, it will all be seriously compromised unless the systems designed to protect people with disabilities from abuse and neglect are robust, ethical, and put the wellbeing of people with disabilities first.

Investigations, literature and anecdotal evidence demonstrate that abuse and neglect of people with disabilities have been part of disability care from the early days till the present, and that efforts to address it have been inadequate, or have just failed. Most organisations and departments handle complaints 'in house', which creates real or perceived conflict of interest. Dr Tom Artobelli notes that there is a deep feeling of cynicism, scepticism and disappointment in the Australian public about the internal processes and policies used by institutions to deal with allegations of (sexual) abuse. In short, there is a reluctance to trust institutions that deal with these matters internally.[58]

Fear is one of the principal reasons for the lack of reporting of cases of abuse and neglect. Fear of retaliation, discrimination, and social exclusion, the fate generally suffered by whistle blowers. Ian Boardman, Queensland Public Advocate 2000-2005, observed that when he first arrived in Brisbane, the most striking characteristic of the broad socio-political culture was its unusually punitive nature. It did not matter where he ventured, people were afraid to speak out for fear of being punished.[59] There are reasons to believe that the culture in many other states of the commonwealth is not a great deal different. It is distrust of the integrity of the current dispute resolution system that has created an – unwilling - acceptance of a culture of neglect and abuse.

Another reason for not complaining is the lack of capacity of service users and other stakeholders to complain effectively, which may well be reflected in little mention of the matter in submissions to the Committee.

What community and people with disabilities and other stakeholders are looking for is a system that is independent, ethical, and fair. A system where people who report wrong doing are the heroes, not the villains. A system that people can trust. A system where the service users' well being is the highest priority.

To be independent this system needs to be part of the human services sector, but independent from it. Similar to Family Relationship Centres which - although part of the fabric of the communities in which they operate - are established by a federal act as part of the Attorney General's department. Its budget should also be guaranteed by an act of parliament to avoid political interference and 'death by administration'.

As is the trend in family law, as expressed in the system of Family Relationship Centres, the process must be non adversarial, and about problem solving, rather than finger pointing. Processes must reflect respectful relationships, and collaboration and co-production principles.

Albert Einstein said that the problems we have created can not be solved with the level of thinking that created them.

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[57] Bramston Training and Consultancy, *Getting it right*, p25, 2008/09

[58] Altobelli, T., Institutional Processes for dealing with allegations of sexual child abuse, 2003, P3 http://www.aic.gov.au/conferences/2003-abuse/altobelli.pdf (sighted 080408)

[59] Boardman, I., Challenging Behaviours, 2005, P19

Blackstone’s maxim of 1765 states that ‘it is better that ten guilty persons escape than that one innocent should suffer’.[60] It confirms that the focus then, as it is now is on the defendant: victims of crime are almost invisible. Louise Casey, the first commissioner for victims of crime in England and Wales, says the criminal justice system treats victims as a poor relation and an afterthought. Too often victims found themselves a "sideshow" as police, prisons, lawyers and the courts focused on the offender.[61] It is the level of thinking that created the problem.

Within the Disability sector the new priority in the new thinking should be about the victim. It is about protecting the vulnerable from the risk of suffering further harm, rather than about punishing the defendant. It means that we must challenge the assumption of ‘innocence until proven guilty’ as that leaves the door open to further abuse until a final outcome has been decided – and this can be a long time!

Proof

There seems to be a belief that standards of proof are absolutes: ‘Beyond reasonable doubt’ in criminal cases, ‘on balance of probability’ in civil cases. But is this so?

Dorothy Kagehiro, Research Psychologist and Consultant, writes that the standard of proof refers to the degree to which the trier of fact must be satisfied that the necessary facts have been established, and that this varies from case to case. The lowest or least stringent standard of proof, preponderance of the evidence, is used in most civil cases and concerns whether or not the existence of a fact is more probable than its nonexistence. The determination of what standard of proof applies in a particular case reflects a judicial or legislative allocation of the risk of error between the disputing parties. The higher the standard of proof, the greater the risk of error that has been placed on the initiating parties.[62]

This, in turn, reflects a determination that the protection of defendants' rights or interests at stake in the litigation is much more important to society than plaintiffs' interests (Cleary, 1972).[63] That is the ‘old’ thinking. In the new thinking the plaintiff’s interests come first, as it is the party with the most to lose.

Professor David Hamer of the University of Queensland, says that if a plaintiff proves her case to a probability of 60 per cent, a verdict will be rendered for the plaintiff and, in the factfinder’s view, this verdict will probably be correct. If ten plaintiffs proved their cases to a level of 60 per cent, all would succeed. Six of these verdicts would be expected to be factually correct, and four factually incorrect, though which were which would be unclear. If the standard were raised to, say, 65 per cent, the defendant would be successful in each of the ten cases. However, the fact-finder would then consider only four verdicts to be factually correct, and six to be factually incorrect. By increasing the standard of proof, the subjective expected rate of factually correct verdicts would be reduced.[64]

The ordinary civil case is symmetrical, says David Hamer.[65] The plaintiff and the defendant have an equal stake in the proceedings. Arguably, where this symmetry is not present and the defendant has more at stake than the plaintiff, the standard should increase or an intermediate standard should be imposed. As abuse and neglect are forms of misuse of power, the more vulnerable the plaintive, the

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[60] William Blackstone, cited Hamer, D., Probalistic standards of Proof, 2004

[61] Casciani,D., Crime victims treated like the 'poor relation' , BBC News, 200710

[62] Kagehiro, D., Defining the standards of proof in jury Instructions, 1990

[63] Cleary, 1972; In re Winship, cited Kagehiro, D., Defining the standards of proof in jury Instructions, 1990

[64] Hamer, D., Probalistic standards of Proof, 2004

[65] Hamer, D., Probalistic standards of Proof, 2004

more he has to loose if the decision goes against him. A non verbal person with a profound intellectual disability and also epilepsy for example, is far more dependant on a support worker than a sporting wheelie. In the new thinking where the plaintive is the vulnerable party, and has the most to loose, the standard should be reduced, to reduce the risk of error, and it may be argued that the standard of evidence should be proportional to the power differential between the parties.

Another significant factor is that hard proof of wrong doing is very difficult to get, particularly with people of reduced capacity, and or non verbal, as – most of the time - they are not considered credible witnesses. An added difficulty is that a person with a disability is usually only attended by a single support worker. This creates the problem that abuse allegations can rarely be corroborated. This is especially significant for people with an intellectual disability. They rely on 'divine intervention': the one occasion that a person of capacity is present at the time of an incident, and this person recognising it as a misuse of power, and this person being prepared to make a written complaint. It is rare for all these planets to be in alignment at the same time, and because of this abuse causing major damage, physically, socially and emotionally, can go on for a long time without being detected.

Where 'beyond reasonable doubt' is about establishing facts, balance of probability is about establishing trends. Most certification - from a driver's license to a commercial pilot's license to the license to practice medicine, or be a plumber - although ostensibly about competence, in reality is an examiner's, or panel's judgment on safety*. "Is this person safe to undertake what he intends to do? What is the risk he will do damage to himself, what is the public risk?"* Nobody can make a judgement on these matters with certainty. A determination, however, can be made on 'balance of probability'. The methods used leading to a conclusion may vary widely, but an assessment of risk is an expectation based on trends.

The level of allowable evidence will bear on the likelihood of getting a correct decision. Hence, as a wrong outcome for very vulnerable people will be most damaging, the required level of proof for them should be lowest. Peter Kennedy, Vice-President Royal College of Psychiatrists, commenting on the Kerr Haslam Inquiry into sexual abuse, said the report recognises that rumour and gossip can be grossly misleading (perhaps 2% are false). However, when rumour, gossip and withdrawn or unsubstantiated allegations refer to the same person repeatedly, the balance of probability grows that patients are being harmed.[66]

Although the standard of proof in these cases is vey low, the trends become very clear, with consequently fewer flawed outcomes.

Some relevant questions that may be asked may be: Is there more than one complainant? How credible is the complainant? Is there a 'get even' issue? Who benefits from not telling the truth?

Introduction of a 'Victim Impact Statement', outlining the anticipated consequences of an acquittal, may well be appropriate.

It follows then that when addressing complaints, the type of information Peter Kennedy refers to must be available. That implies a clear moral and contractual obligation for all such information to be reported and recorded in a national data base.

For the success or failure of the entire reform agenda as outlined in this submission the credibility and integrity of the complaints resolution system will be critical.

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[66] Kennedy, P., Kerr/Haslam Inquiry into sexual abuse of patients by psychiatrists © TPsychiatric Bulletin, 2006

Conclusion

To attempt to repair the present – broken – system will be a mistake. Not only is it beyond repair, but it was no good to begin with! Again, reflecting on Einstein's observation, we need new thinking to break with the – very flawed – past. In our new thinking we must recognise that regardless of differentness we all are equal in our humanity. With that belief we can break down the social construct of disability, and become a tolerant and inclusive community. Prominent American psychologist, Pat Deegan, who also has experienced a serious mental health issue, summed it up when she said: "We say let the mainstream become *a wide* stream that has room for all of us and leaves no one stranded on the fringes"[67].

This submission outlines a reform agenda based on three well proven systems: Local Area Coordination, Self Directed Services, and MediCare.

Additionally it proposes a system of oversight and accountability that may be thought of as new, but is based on principles of natural justice. This system of conflict resolution will be a natural fit with – and critical to the success of – the proposed system of reforms as it supports the same values base.

Recommendations

1) An interface between people with disabilities and funding providers, based on the West Australian system of Local Area Coordination
2) Due regard be given to the need to grow this LAC culture, and to protect it from becoming compromised by prevailing public service cultures
3) Introduction of self directed services, based on the inControl system as an option to service users and service providers
4) A symbiotic relationships of co-production between people with disabilities funders, and service providers, through the devolution of powers, and based on LAC and community development principles
5) A non-adversarial complaint system in which protecting the vulnerable is the primary goal
6) The system be a universal, national, one
7) A broad, whole of government approach
8) A whole of life approach with a seamless interface with early intervention and age care
9) Very broad eligibility criteria, definitely including mental health
10) A MediCare system of funding, with capacity to vary the rate to meet cost variations
11) Hiring principles throughout with the following values not-negotiable:
    - a sound values base (positive and contemporary attitudes towards people with a disability)
    - understanding of and commitment to the values and charter of local area coordination
    - the ability and willingness to develop and maintain positive and trusting relationships with people with disabilities and their families
12) A high level of training and mentoring to address the unpreparedness for the radical changes being introduced. by service users, service providers, funders and the community at large
13) Due regard for Murphy's Lament: "Why is there never time to do the job properly, but there is always time to do it twice!". Getting it right is more important than doing it quickly

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[67] Deegan, P., Recovery as a journey of the heart, 1996

14) Legislation. Frequently legislation formalises changes in community thinking, perceptions and beliefs, however there are times where government through legislation must lead. Examples are compulsory seat belt regulation, and the move towards use of solar power. In both cases legislating unchosen change speeded up acceptance and implementation. The NDIS for many is about unchosen change, and that includes key players in the sector. Government leading through strong legislation will ensure quicker acceptance, and hopefully understanding, and shortened time lines for implementation

This submission proposes a transformational change through an integrated plan. Implementing or cherry picking bits of it will result in failure as the proposed plan is not compatible with the thinking, systems and practices of the past.

Implementing the proposed system carefully and deliberately is relatively risk free as it is based on proven systems, and will contribute in a major way to creating an inclusive society in our country.

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