

Inquiry into a long-term disability care and support scheme

***Submission Supplementary
to
“From Charity to Equality”***

In response to the

Productivity Commission Draft Report on Disability Care and Support 280211

By John Homan,

speaking for the Capricorn Community Development Association, Rockhampton

“Sharpen the Saw”¹

The Productivity Commission’s (PC) draft report on Disability Care and Support (280211) in many ways shares the strategic direction expressed in the Capricorn Community Development Association’s submission to the PC (no 599). This submission focuses on issues in the Draft Report that CCDA believes need to be addressed for the National Disability Insurance Scheme (NDIS) to provide optimum outcomes for people with disabilities, their families, the community, and the sector as a whole. It is consistent with CCDA’s previous submission “From Charity to Freedom”² (No. 599)

In its report into Caring for Older Australians the PC dot-points its objectives for future policy:

“To guide future policy change, the aged care system should aim to:

- *promote independence and wellness of older Australians and their continuing contribution to society*
- *ensure that all older Australians needing care and support have access to person-centred services that can change as their needs change*
- *be consumer-directed, allowing older Australians to have choice and control over their lives*
- *treat older Australians receiving care and support with dignity and respect*
- *be easy to navigate — Australians need to know what care and support is available and how to access those services*
- *assist informal carers to perform their caring role*
- *be affordable for those requiring care and for society more generally*
- *provide incentives to ensure the efficient use of resources devoted to caring for older Australians and broadly equitable contributions between generations.*

*This report offers a detailed plan for the implementation of a new policy framework which encapsulates these objectives”.*³

The first six items are equally relevant to people with disabilities, however it is disappointing that no such summary has been included in the Draft Report of 280211, encapsulating the Commission’s

¹ Covey, R. S., 1989, The 7 Habits of Highly Effective People

² From Charity to Freedom, Homan, J. 2010, Capricorn Community Development Ass.

³ Caring for older Australians, Productivity Commission Draft Report, 210111, Overview p XXV

vision, and the strategic directions it recommends to achieve optimum outcomes for people with disabilities.

“Begin with the end in mind”⁴

The best society we can aspire to is one where all citizens have reached their potential, are on the way to reaching their potential or at least have the opportunity to do so! Or in Maslow shorthand: "What a man *can* be, he *must* be"⁵. For people with disabilities – and other groups of marginalised people – this is more difficult to achieve than for most.

A man ‘becoming what he can be’ is a journey that requires an understanding of where the journey may lead, and strategic capacity and the authority to make the choices that will keep him on course. It requires self-awareness and empowerment.

There are many impediments to people with disabilities making this journey, both external, embedded in community, and the ‘system’, and internal, personal ones.

The traditional charity model of disability care, and normalisation are major roadblocks. It has created a social construct of disability that has shaped community’s and governments’ culture of discrimination, and misuse of power “for the person’s own good”. It has led to a service industry which controls resources, and how they are used, and has generally punished the ‘square-pegs-in-round-holes’. It has disempowered the individual to the point where he becomes a spectator in his own life, denied choices, denied respect, and denied a valued role in community.

People with disabilities exist in an environment where their potential for growth is ignored, and they are denied respect or choices. This is not an environment conducive to developing self awareness, or empowerment.

The Productivity Commission’s Draft Report of 280211 clearly shows a new direction where the people with disabilities have become the main focus.

The question whether the structure and culture of the National Disability Insurance Agency (NDIA) will be risk averse and hierarchal, or a living, evolving, innovative, risk managing organic system, is not clear from the Draft Report.

If it is hierarchal, with authority concentrated at the top of the organisational pyramid, and with the people at the interface with people with disabilities, and the community mere messengers of decisions made at the top, well away from the coal face, then – it will be ‘business as usual and - the NDIA will fail. The pox on Frederick Winslow Taylor!⁶

If “What a man *can* be, he *must* be” is the light on the hill, and empowerment is a way point on the journey towards that goal, then there is a compelling case to embrace the alternative system. To turn the organisational pyramid upside down, with the Assessor/Coordinators, the interface with people with disabilities and community, at the top, and the rest of the organisation supporting them.

⁴ Covey, R. S., 1989, *The 7 Habits of Highly Effective People*

⁵ Maslow, A. H. (1943). A Theory of Human Motivation, *Psychological Review* 50, 370-96.

⁶ Frederick Winslow Taylor has a lot to answer for said Stephen Long (Taylorism in an IT world, Australian Financial Review, 1989) Taylor’s Principles of Scientific Management removed all autonomy and authority from the workplace and transferred it to management, and that way places a dead hand on innovation and creativity.

Fortunately this is not a new revolutionary idea! It is how the West was won.

Local Area Coordination was pioneered in Albany - WA in 1988, and since spread through the entire state, and has been developed, fine tuned, road tested and reviewed over more than twenty years. Its Leit-motif is 'relationships'. Respectful (equal), trusting, long term relationships. It has brought to reality the traditional aphorism:

*'Don't walk in front of me I may not follow.
Don't walk behind me I may not lead.
Walk beside me and just be my friend.'*

Prof Angus Buchanan⁷ in his 2000 research project in Western Australia, found that the empowerment levels of people with and without funding were equally high. A primary support service accessed by all families in his study is Local Area Coordination. It would appear, Buchanan says, 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.

If the NDIA's objectives are the same as those of the Western Australian system of Local Area Coordination, it does not seem far fetched for the NDIA to adopt Local Area Coordination in Western Australia as its 'pilot' project, rather than re-invent the wheel. With so much experience and knowledge – of successes and failures – it will then be possible to propagate this system in communities east of the Nullabor.

The outcome of his research may have been a surprise to Angus Buchanan, but Local Area Coordination was always about 'more than the money'.

The following quotes are from "It's about more than the money, Local Area Coordination Supporting People with Disabilities" by Eddie Bartnik, and Ron Chalmers, published in 'Co-Production and Personalisation in Social Care', 2007⁸

"The LAC Charter is to "develop partnerships with individuals and families as they build and pursue their goals and dreams for a good life, and with local communities to strengthen their capacity to include people with disabilities as valued citizens". P 25

Local Area Coordination can be described as a generalist or eclectic approach. It exhibits elements of individual coordination, personal advocacy, family support, community development and direct funding. The unique quality, and much of the advantage, of Local Area Coordination 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. P 28

The role of Local Area Coordinators:

⁷Buchanan, A., 2000, The predictors of empowerment for parents and carers of people with intellectual disabilities within the direct consumer funding model.

⁸ Bartnik, E., Chalmers, R., It's about more than the money, Local Area Coordination Supporting People with Disabilities, 'Co-Production and Personalisation in Social Care', Jessica Kingsley Publishers, ISBN 978 1 84310 558 9, 2007

- *Build and maintain effective working relationships with individuals, families and their communities.*
- *Provide accurate and timely information. Assist individuals, families and communities to access information through a variety of means.*
- *Provide individuals and families with support and practical assistance to clarify their goals, strengths and needs.*
- *Promote self advocacy. Provide advocacy support and access to independent advocacy when required.*
- *Contribute to building inclusive communities through partnership and collaboration with individuals and families, local organisations, and the broader community.*
- *Assist individuals and families to utilise personal and local community networks to develop practical solutions to meet their goals and needs.*
- *Assist individuals and families to access the supports and services they need to pursue their identified goals and needs. P 26*

Consistent with the theory that underpins Local Area Coordination, however, direct funding is viewed as an adjunct to family and community based supports rather than as the primary solution to meeting needs⁹. P27

Direct Funding to individuals and families through the LAC program varies from small amounts of non recurrent discretionary funding administered directly by the LAC, through to small Flexible Family Support packages (up to \$5000) and then larger packages related to Intensive Family Support, Post School Options or Alternatives to Employment and Accommodation Support (all recurrent packages). The self management of direct funding by individuals and families through LAC operates within the LAC Framework plus an additional Accountability Framework (Disability Services Commission, 2005). P29

Local Area Coordinators are drawn from a wide range of backgrounds and professions (e.g. social work, psychology, education, therapy, nursing and community work). The key quality sought in a prospective Local Area Coordinator is a contemporary values base which reflects the vision and principles of the LAC program. Wherever possible, LACs are recruited from their local communities. P28

Some important messages regarding limitations of the approach:

- *the Program is only as good as the individual LAC that the person has, hence staff selection, quality and consistency is critical;*
- *if you give the LAC too many people to work with, you lose the personal touch and emphasis becomes too much on critical issues;*
- *too much bureaucracy and emphasis on funding takes the LAC away from core business and direct contact; and*
- *people from indigenous and culturally diverse backgrounds may require additional strategies in order to gain effective access. P 34*

The LAC program in Western Australia has had a deliberate strategy to preserve core values and purpose yet at the same time stimulate and encourage progress and change.

⁹ This is supported by the Buchanan study.

This methodological approach has been inspired by the work of Michael Kendrick on safeguards (see Kendrick, 1997) and also the management text “Built to Last: Successful Habits of Visionary Companies”, Collins and Porras, 1994). P 34

An analysis of the past three five year strategic plans clearly shows a clear trend away from an emphasis primarily on service delivery and coordination (1995-2000) through to an increasing emphasis on strengthening individuals/families and carers, family leadership and welcoming communities (2000-2005) and then most recently citizenship and the importance of a sustainable community response (2005-2010). P 36

Over 70% of all care and support provided to people with disabilities comes from family and friends. It is simply not possible for the government and formal service delivery systems to replace this support and hence, from a business case perspective, it is essential that the informal system of family and friends is supported to the greatest extent possible. This necessity combined with the strong value-for-money evidence for the Local Area Coordination approach, constitutes a compelling business case. P36

Several external evaluations of both LAC in Western Australia and elsewhere – most particularly Queensland – as well as internal evaluations and the value for money study commissioned as part of this review, have confirmed that the LAC model provides value for money outcomes not matched by any other areas of disability services delivery.”¹⁰ P34

Protecting the integrity of the NDIS/NDIA

The integrity of any system, and that includes the NDIS, must be protected by a conflict resolution system that people trust.

The Caring for Older Australians draft report lists under its concerns: “insufficient independence of the complaints handling process”¹¹ This sentiment is echoed in the disability sector.

People with disabilities have suffered internally administered conflict resolution systems for many decades, and are deeply suspicious of them. People understand conflict of interest, and they understand that whistle blowers are seen as a threat, rather than an avenue to address misuse of power, unfairness or other failings in the system.

For a conflict resolution system to have credibility and be trusted, people lodging a complaint must be welcome, and be treated with respect. To achieve this the system must:

- be totally independent from the NDIA (with the Department of Justice may be?);
- protect the vulnerable as its first priority, and
- regard punishing the guilty as a lower order requisite;
- protect and be seen to protect people making a complaint;

¹⁰ Bartnik, E. and Psaila-Savona, S. (2002), *Value for money*. Paper for the Local Area Coordination Review Steering Committee. Western Australia.

¹¹ Caring for older Australians, Productivity Commission Draft Report, 270111, Overview p XXIII.

- create a culture where misuse of power (the core of almost all complaints) is unacceptable and lodging a complaint to protect the vulnerable is the normal and honourable thing to do.

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.

More is said about conflict resolution in the Capricorn Community Development's (CCDA) primary submission 599, "From Charity to Freedom", ¹² P 16

Compliance Costs

*Funding for service providers is often uncertain and inadequate, and comes with unnecessary compliance burdens, stifling innovation and flexibility.*¹³ P 6

The costs associated with accountability, reporting, and compliance have increased exponentially over the years, and are an ongoing concern in the human services sector. This is felt to have a negative effect on both service providers and consumers.

The questions are:

- Has it lead to improved service outcomes for consumers? Buchanan¹⁴ says no: A lessening of the control of service systems over the lives of people with disabilities and their families is viewed as a necessary condition for the achievement of greater empowerment.
- Has it reduced the use of resources by service providers for other purposes than its consumer's benefits? May be.
- Thinking small: What are the minimum requirements that make the system accountable, transparent, enables collection of useful statistical data, and has a minimal controlling effect on the lives of people with disabilities

The Queensland Council of Social Services (QCOSS) has just launched a survey of not for profits in the human services sector to determine the cost of compliance for services in the state. It states that:

*"there are over 50 different sets of quality or service standards for community services and health NGOs. Assessing, complying and reporting against them costs staff time, money and organisational resources. But we don't know how much it costs".*¹⁵

Mental Health

¹² From Charity to Freedom, Homan, J., 2010, Capricorn Community Development Ass.

¹³ Disability Care and Support, Productivity Commission Draft Report, 280211, Overview

¹⁴ McKnight, 1995; Riger, 1993; Rousseau, 1993; Tyne, 1994, quoted by Buchanan, A., 2000, The predictors of empowerment for parents and carers of people with intellectual disabilities within the direct consumer funding model.

¹⁵ Email from QCOSS, 250311

People with mental health issues must be included in the NDIS. Mental illness has different rhythms than other disabilities as they may be episodic and may require more intense clinical support. To further confuse matters, many people with disabilities have a dual diagnosis. John Pini (UniCare) observed at the Canberra hearings:

*“A significant number (of people with disabilities) 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”*¹⁶

Including mental health in the NDIS will enable a whole of person support system, rather than a fragmented, silos approach. It will promote a trust based collaboration between the medical and social support systems.

Group homes (or “Institutionettes”)

*Specialist accommodation support, such as group homes and alternative family placement.*¹⁷

Group homes have been popular with service providers because of their cost effectiveness, and although an improvement on institutions, are for most people with disabilities a poor option.

The Shut Out report¹⁸ has collated much criticism of group homes:

“Many people with intellectual disability live in group homes, and while some would argue that this is an improvement on the previous large institutional arrangements, these environments still congregate and segregate people in a way which inhibits community inclusion.

Further, people living in these arrangements have very little choice about who they live with, whereas non-disabled community members who choose to share accommodation with others generally do have this choice ...

It is reasonable to argue that very few people living in group homes would choose to live in such a setting if they had a realistic choice. It is a compromise brought about by necessity, as they do not have enough support through funding for paid support, even augmented by their family and informal support networks, to live in their own home...

The concept of community living for people with intellectual disability is a much richer concept than a mere physical presence in a community setting, which by itself does not guarantee community integration and inclusion.

As support workers often work alone, there remains significant risk of abuse and neglect.”

In her address to the National Press Club Dr Rhonda Galbally¹⁹ gave examples:

¹⁶ http://www.pc.gov.au/__data/assets/pdf_file/0010/99946/20100713-canberra.pdf

¹⁷ Disability Care and Support, Productivity Commission Draft Report, 280211, Overview p 21.

¹⁸ SHUT OUT: The Experience of People with Disabilities and their Families in Australia, Dr Rhonda Galbally, 2009, (2.3.4 Lack of housing options), P 27

- *young people living in group homes - forced to go to bed every night at 5 pm because the staff say so, unable to help themselves to food from the locked fridges, unable to go out for a walk through the locked doors.*
- *a young man who was assaulted by a fellow resident in his group home, but who continued to live under the same roof as his abuser because there was nowhere for either of them to go.*

¹⁹ Dr Rhonda Galbally AO, Chair, National People with Disabilities and Carer Council, Address to the National Press Club, Canberra, 2009

There are other issues:

- 'community access' tends to be as groups, regardless of diverse interest (again cheap) It frequently condemns people to a merry-go-round between shopping centres, McDonalds and public parks.
- There is convincing anecdotal evidence that people with higher skill levels tend to dumb down to the level of those with the least skills.
- The Queensland Department of Housing has concerns about shared tenancy arrangement in its public housing, where the tenants have no previous relationships, and has extensive procedures to ascertain compatibility of prospective tenants.²⁰
- Often people are put together in a group home on a temporary basis, regardless of compatibility, to meet a crisis. Once the pressure is off this arrangement then tends to become permanent.

Group homes may be a viable option where compatibility of residents is assured, but should generally be viewed as a last, and temporary solution.

Respite

Respite care provided in a community setting similar to a 'group home' structure is known as 'centre based' respite in Queensland and as 'cottage style' respite federally. For centre based respite to be a success for the person with a disability (and the family too!) compatibility of guests and staff is at all times a major consideration.

For many people, particularly those with behavioural issues, like autism, AD(H)D, or Asberger, a centre based respite facility is inappropriate. This group needs respite in a one on one setting.

Employment

. . . the NDIS would fund 'job readiness' programs (such as the 'Transition to Work' program in NSW) and specialised employment services.²¹ P 22

It is critical that, once a consumer is in employment, the NDIS funds follow up support and monitoring.

Moving from the DSP into employment has risks and may fail. Many have been reluctant to make the shift as entitlements attached to the DSP, like health benefits, psychological and other supports from the department, taxi subsidies, are lost. Retaining the DSP during a trial period, with may be a review after a year, and retention of benefits over this period may be a better option, as it provides a safety net, and if the trial is unsuccessful, a way back.

²⁰ Queensland Department of Housing - Operating manual - 2000

²¹ Disability Care and Support, Productivity Commission Draft Report, 280211, Overview.

Workforce issues

The Commission is sceptical of imposing any additional requirements for credentials and training of the disability services workforce. In particular, there should be no minimum training requirement to work as a personal support worker.

These support workers are the most important group in that workforce, and the essential skills they bring — empathy, a capacity for listening and social skills — are intangible and not easily created through training. Moreover, the most important ‘training’ of workers is often by the person with a disability and their families. (It should also be emphasised that the overwhelming current source of care is unpaid and usually untrained family carers, who are usually preferred by people with a disability.)²² P 39

Empathy, a capacity for listening and social skills, as well as integrity and punctuality are elements of a support worker’s value base, and not negotiable. They are however not indicative of a person’s capacity to perform the tasks required.

It is critical that a person’s capacity is assessed, and if inadequate, is raised to an acceptable level, in areas like:

- least restrictive practices,
- strength based practice,
- risk management,
- workplace health and safety,
- consumers’ rights,
- first aid,
- defining boundaries in relationships²³, and
- creating an empowering environment through respectful (equal) relationships.

Raising a person’s capacity may be achieved by different means, formal, or informal training, mentoring, or supervision.

It is important that once capacity is assessed as satisfactory – or better - this is recognised as a professional attainment.

Relying on people’s inherent attitude and capacity only, will return us to the days of Sairey Gamp.²⁴

- It will devalue the sector, which has worked very hard to raise its profile to a professional level.
- This lower status will affect workers’ sense of worth, and will inhibit attempts to improve pay and conditions, which
- may exacerbate workforce shortages.
- People of good intent, but without adequate knowledge and capacity will put consumers at risk, and it may not be possible to hold them to account.

Even where an entitlement is cashed out, workers engaged by the consumer or family need to have this minimum training, mentoring, and assessment of capacity. This is particularly important when

²² Disability Care and Support, Productivity Commission Draft Report, 280211, Overview

²³ Healthy Boundaries, Bramston Training & Consultancy, 2009

²⁴ Sairey Gamp is a Charles Dickens character in his novel Martin Chuzzlewit. Sairey is an alcoholic who works as a nurse, midwife, and layer-out of the dead. Even in a house of mourning she has little regard for the person to whom she is there to minister; and she is often much the worse for drink.

working in isolated areas with minimal peer support, and when supporting people of reduced capacity like children, or people with an intellectual disability or mental illness.

Block Funding

However, block funding may persist in exceptional circumstances, such as pilots of innovative services, in some rural areas where markets might not support the provision of any service, or where there is a need to build longer term capacity, such as Indigenous specific services.²⁵ P 40

Block funding is advantageous in centre based respite services as it gives flexibility and a capacity to respond to emergencies.

There is opinion in the mental health sector that favours block funding as it provides flexibility to support consumers when needed, as mental illness is frequently episodic.

Rural and remote

. . . in some cases, non-government organisations and private operators may be unwilling or unable to operate (though presumably they would often do so if prices were set sufficiently high)²⁶ P 42

It must be recognised that cost structures for delivering services in rural and remote locations are very different from those in major population centres: Extra travel costs, and training costs are just two examples. The NDIS needs to have the flexibility to deal with this in a consistent way (ARIA²⁷ scores may be of help here as a comparative tool)

²⁵ Disability Care and Support, Productivity Commission Draft Report, 280211,

²⁶ Disability Care and Support, Productivity Commission Draft Report, 280211

²⁷ Accessibility/Remoteness Index Of Australia, a geographic approach to measuring the concept of remoteness and the creation of a standard classification and index of remoteness that covers the whole of the country. <http://www.health.gov.au/internet/main/publishing.nsf/Content/health-historicpubs-hfsocc-ocpanew14a.htm>

Recommendations²⁸

- 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

John Homan
Yeppoon
060411

²⁸ From Charity to Freedom, Homan, J., 2010, Capricorn Community Development Ass. P19

References

- ARIA, Accessibility/Remoteness Index Of Australia
<http://www.health.gov.au/internet/main/publishing.nsf/Content/health-historicpubs-hfsocc-ocpanew14a.htm>
- Bartnik, 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
- Bartnik, E. and Psaila-Savona, S. (2002), Value for money. Paper for the Local Area Coordination Review Steering Committee. Western Australia.
- Buchanan, A., 2000, The predictors of empowerment for parents and carers of people with intellectual disabilities within the direct consumer funding model.
- Caring for older Australians, Productivity Commission Draft Report, 2010
- Covey, R. S., 1989, The 7 Habits of Highly Effective People
- Disability Care and Support, Productivity Commission - Draft Report, 280211.
- Email from QCOSS, 250311
- Healthy Boundaries, Bramston Training & Consultancy, 2009
- Homan, J., From Charity to Freedom, Capricorn Community Development Ass., 2010
http://www.pc.gov.au/__data/assets/pdf_file/0010/99946/20100713-canberra.pdf
- Long, S., Taylorism in an IT world, Financial Review, 1989
- Maslow, A. H. (1943). A Theory of Human Motivation, Psychological Review 50, 370-96.
- McKnight, 1995; Riger, 1993; Rousseau, 1993; Tyne, 1994, quoted by Buchanan, A., 2000, The predictors of empowerment for parents and carers of people with intellectual disabilities within the direct consumer funding model.
- Operating manual, Queensland Department of Housing, 2000
- SHUT OUT: The Experience of People with Disabilities and their Families in Australia, Dr Rhonda Galbally, 2009.