

Reasonable and Necessary Support

The 'Needs Assessment Process

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From the Old to the New

“Current disability support arrangements are inequitable, underfunded, fragmented, and inefficient and give people with a disability little choice” says the Productivity Commission in its report on Disability Care and Support.

It is a reflection on out dated but enduring, centuries old, ‘alms for the deserving poor’ charity system. “Charity maintains poverty” said Mohammad Yunis.¹ The poverty lies in the inequality that charity creates: we are all equal, but some are more equal than others. This inequality frequently leads to discrimination, social stigma, intimidation, bullying, neglect and abuse. The misuse of power.

Getting support is a competitive process due to scarcity of resources. The person with a disability needs to demonstrate that he is a more deserving poor than others. This is an anathema: when we love a person, disabled or not, we naturally want to show him in the best possible light. When applying for support however, we are forced to show as desperate a case as we are capable of creating. It is abhorrent, humiliating and demeaning, a Judas act of betrayal of the person we love and support with loyalty, respect and commitment.

It is not surprising that, against this background, people with disabilities and supporting families dread the process of having their support needs assessed.

Even when successful, success is only relative as choices are limited, and gate keepers are firmly in charge. Worse still, many services offered are of a maintenance, ‘filling in time between meals’, nature.

There has been a growing awareness that care and support for people with disabilities is way out of step with community expectations. Government listened, appointed the Productivity Commission to conduct an investigation, and, it is hoped, that the outcome will be a system that is radically better than the current one.

Two critical element that define and drive the changes are:

1. that accessing resources will no longer be a competitive process. Funding will become an entitlement, like Medicare, education and unemployment benefits.
2. people with disabilities will be able to control their own funding, and with it their own lives. They will be able to build and pursue their goals and dreams for a good life. Being a participant, rather than a spectator in their own lives will build their self esteem and confidence, and will equip them to become valued members of their communities.

These are transformational changes.

¹ Mohammed Yunis, Founder of the Grameen Bank of Bangladesh, Nobel Peace prize winner, 2006.

- Allocation of resources is no longer a competitive process, and so there is no longer a role for 'gate keepers'.
- NDIS (the funder) has delegated power to people with disabilities by giving them control over funding, (within parameters of equity and accountability).
- *'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'.²*

Relationships

For these changes to become an on the ground reality, the change from a top down, hierarchal system, to one based on relationships is critical and non-negotiable. Respectful relationships, as in equal, credible and trusting, are the foundation for 'good life' outcomes for people with disabilities .

The crucial importance of relationships in all our lives, people with disabilities included, can not be overrated. Relationships enrich people's lives, as well as community and society.

English anthropologist Daniel Miller interviewed in depth 36 people on a single south London street several times over many months. Some observations:

"A full life does not come from being rich, filling your house with a lot of things, nor from being busy, and filling your day with lots of activity. A full life comes from having a number of significant and fulfilling relationships that support you and give your life purpose, someone to share experiences with, good and bad".

"Instead what they cherished were their relationships: the social networks which sustained them, provided a sense of identity, purpose and rhythm to their lives. Happiness and well being does not come from our freedom to break free of bonds but instead to commit ourselves to relationships. ³Our sense identity does not simply come from within - what we want to be – but from our interconnectedness and interdependence".⁴

The elephant in the room

Many support services and government departments actively discourage, or forbid, the development of personal relationships between carers and clients. This harks back to the time when people with disabilities were locked away in institutions, isolated from family and friends, and out of sight of community. The perception in the medical community was that 'children like that' don't need love' (Smith 1997 cited Croft 2000, p. 170) and was used as a justification for institutionalisation.

Although the justification has changed over the decades, the underlying philosophy and practice have not. Paton and Homan challenged this view. ⁵

² Poll, C., KeyRing Living Support Networks and Neighbourhood Networks, in 'Co-Production and Personalisation in Social Care', 2007

³ Happiness Paradox

⁴ Leadbetter, C., WITH relationships and the common good, 2008.

<http://www.charlesleadbeater.net/cms/xstandard/With1.doc>

⁵ Paton, S., Homan, J., Learning with Amanda, The International Conference for Engaging Communities, Brisbane, (2006), <http://www.engagingcommunities2005.org/abstracts/Paton-Sandy-final.pdf>

“Operating on a traditional paradigm, many support services and government departments actively discourage the development of close personal relationships between carers and clients. It is seen firstly, as ‘not professional’ and, in line with the medical model of disability, appears aligned to the doctor/patient model of relationships and in many instances is focused solely on maintaining the physical integrity of the person. Secondly, relationships between staff and clients are frequently presented as placing the staff member in the position of ‘conflict of interest.’ We must ask ourselves: “How can this be?”, if the institution, agency or service provider is truly focused on working in the client’s best interests and providing quality of life, as well as physical care”.

Di Muirhead and Karen Williams of Bramston Training and Consultancy support the view that personal and professional relationships are desirable and can co-exist without conflict or perceived conflict of interest, provided certain rules and boundaries are put in place. (attachment A)

*“There are differences between relationships that are formed in our personal lives and those that are formed with people being supported. It is important to highlight these differences, as they are the defining features that separate and create the boundaries within which support relationships are formed”.*⁶

Is the elephant still in the room? The Productivity Commission in its Overview of the Draft Report makes a recommendation about the relationships between the assessor and the disabled person:

- *To promote independent outcomes, assessors should not have a longstanding connection to the person.* (P70)⁷

This recommendation would deny the establishment of the respectful and trusting relationships that are so critical to good outcomes. In its final report’s Overview the Productivity Commission has come to a different conclusion:

- *“The people making assessments would need to be independent from the client”*⁸

This recommendation accepts the argument that it is possible to have personal and professional relationships coexist without conflict or perceived conflict of interest, provided certain boundaries are put in place. ‘Good bye elephant!’⁹

Relationships do not just happen, they grow organically, and for them to grow rich and strong communication is the critical element in the equation. As a minimum they must embrace common values and speak a common language. Equality, mutual respect and credibility are the ingredients that make a trusting relationship possible. A relationship that is facilitative, not controlling; co-operative, not confrontational.

Communication is not just about the spoken word. Body language, emphasis, passion, tone of voice all contribute, many of them abstract and open to interpretation¹⁰. The quality of the communication is dependent on the capacity of the person it is directed at to interpret the message correctly, and that in turn relies on the quality and depth of the relationship.

Assessors

The Productivity Commission mentions assessors several times in its report, mainly in a ‘thou shall not’ tone, but does not define the qualities it seeks in assessors for them to be successful in their

⁶ Muirhead, D., Williams, K., Getting it right, Workshop for service leaders, Bramston Training and Consultancy, 2008-09

⁷ Productivity Commission, Draft Report, Overview, Recommendation 5.4., P 50.

⁸ Productivity Commission, Report, Overview, P 20.

⁹ Recommendation 5.4 in the draft is still in the final report as recommendation 7.4 (P 70) (an oversight?)

¹⁰ Many, particularly intellectually disabled, people have no or very little speech, and/or comprehension.

role as the interface of the NDIA (the funder) and the person and families with disabilities. The ten references to Local Area Coordination (LAC) in West Australia in the Overview document may be significant. (Attachment B) It may indicate the Productivity Commission preferred option. It may well point to the LAC as system that is well established and proven, to have the values, attitudes, experience and integrity to become the interface between funder and client. It is not a long stretch to include needs assessments, and monitoring of the packages.

Local Area Coordination in WA is not new. Since its start in Albany WA in 1988, it has developed and grown to this day. Local Area Coordinators are now the interface with the Disability Commission throughout WA.

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.¹¹

Local Area Coordination is not a model, it is a system. Systems by definition are a 'complex whole'; they are flexible and pluralistic. Systems operate effectively on situational ethics that recognise variables, interconnectedness and ambiguity.¹²

There are no specific skill sets that cover the complexity of the LAC's role, and so LAC's come from a variety of backgrounds and disciplines. They are selected on other criteria than their skill sets: a contemporary value base, ethics, emotional intelligence, capacity to build and maintain relationships are all key qualities sought in prospects. There is a great awareness that the program is only as good as the individual LAC that the person has, hence staff selection, quality and consistency is critical.

LACs work with children and adults of all ages and stay with people across the major transition points of life. It is the nature and quality of this ongoing relationship, and having one point of contact for local people that is reflected consistently in satisfaction ratings with the LAC program.¹³

Their close relationships with people with disabilities over long periods of their lives makes LAC's particularly suitable to be needs assessors, and also monitor the appropriate use of packages. Their knowledge and understanding of the individual's and family's circumstances gives them the insights that enable superior outcomes.

Monitoring the use of the package is less to do with fraud or dishonesty, than with being able to fine tune elements in order to get better outcomes.

*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.*¹⁴

Assessment: the Process

In 2003 'in control' was established as a vehicle to promote self directed services in Great Britain. By November 2007, 2300 people were receiving personal budgets using the "in control" model.

¹¹ 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

¹² Concise Oxford Dictionary, p. 1174

¹³ 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

¹⁴ Leadbeater, C., et al, Making it Personal, Demos, 2008

In 2008 Demos¹⁵ published a comprehensive research report on self directed services in Britain with a particular focus on “in control”.¹⁶

The Productivity Commission had a close look at ‘in Control’,¹⁷ and appeared critical of it being funded and administered by local government, rather than nationally,¹⁸

Quoting from the Demos paper:

“The ‘in Control’ assessment process is somewhat different from traditional practice. Budgets up front not at the end of the line. ‘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; in some authorities this can be done over the phone. That self-assessment is checked and quickly translated into a resource allocation: a sum of money.

Under the traditional approach resources are allocated at the end, as the result of the process. Under “in control” people know early on what resources they are likely to have.

That allows them to plan how to use their money and to consider alternatives to in-house or pre-purchased service provision.

Based on the resources available people draw up a self-directed support plan rather than having to accept a care plan drawn up by a care manager. A self-directed support plan describes what matters most to a person, what they want to achieve in their life and how they will use their budget to enact these changes. A traditional care plan is an account of the services an individual will get from the local authority. A self-directed support plan starts from how someone wants to live and then works out the combination of formal and informal, private and public support that will achieve these goals. The aim is to find the best way to fit the services people need into their lives”.

The ‘in Control’ system within the context of Local Area Coordination offers many advantages.

For people with disabilities:

- to have control over their lives is empowering, as it places them in the real world where decisions are made in a frame work of priorities, preferences, and risk management.
- it builds people’s capacity to address their own issues which.
- heightened capacity, and reduces dependencies and
- Builds self-esteem and self worth which in turn
- Removes stigma and validates their inclusion in community.

¹⁵ Demos is the think tank for everyday democracy. We believe everyone should be able to make personal choices in their daily lives that contribute to the common good.

¹⁶ Demos, Making it personal, 2008, <http://www.partnerships.org.au/Making%20it%20Personal.pdf>

¹⁷ PC consultation Brisbane 150710, P 109,

http://www.pc.gov.au/_data/assets/pdf_file/0020/100289/20100716-brisbane.pdf

¹⁸ This is consistent with the PC’s preference for the NDIS to be a national scheme. *“The most inferior option of a ‘federated’ NDIS. In which the Australian Government would provide additional disability funding to state and territory governments and stipulate some common national features, but would otherwise leave state and territory governments “in control” of their own systems. This would be better than current arrangements. However, the system would remain fragmented, and the support received would retain features of the postcode ‘lottery’. Moreover, such an arrangement could easily revert to the current dysfunctional and unfair system, with ‘agreements’ breaking down into disputes about relative contributions, special variations and carve-outs. A loose arrangement would expose Australians to significant risk.*

A federated scheme would not offer people the assurance of high-quality long-term” care and support”. PC report Overview – P 37.

The NDIS also benefits:

- Reduced dependency may be reflected in a lower need for resources.
- People with disabilities designing their own support plan frequently find less expensive solutions than would be recommended in a top down system.
- The Local Area Coordination system is built on relationships and trust since its beginnings. It is reflected in LAC's having authority that is commensurate with their responsibilities. This allows for a flat management system which enhances speed in decision making with low costs.

The old and broken system largely provides a maintenance model services of 'filling in time between meals', a life without a future or hope. The new system provides an environment that takes people on a journey towards their potential, towards a less dependent life that is meaningful and inclusive.

Jeremy Ward¹⁹ posed this question in 2002:

"Why, if we as a general community want our children to love and be loved, to have strong friendships and cherished relationships, to live independently, to contribute to society, to take pleasure in activities of their own choosing, to have full, enjoyable and inclusive lives and to be able to continue to learn and grow, would we expect parents of an intellectually disabled to accept anything less for their child?"

With an NDIS implemented, as intended, we may not have to ask this question any longer.

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¹⁹ Jeremy Ward, 'Pave the way', Mamre Ass. Inc., 2002

Attachment A

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HEALTHY BOUNDARIES

There are differences between relationships that are formed in our personal lives and those that are formed with people being supported. It is important to highlight these differences, as they are the defining features that separate and create the boundaries within which support relationships are formed.

Support relationship characteristics:	Personal relationship characteristics:
<ul style="list-style-type: none"> • The support relationship is a special type of relationship established for a particular purpose 	<ul style="list-style-type: none"> • Personal relationships usually happen by chance.
<ul style="list-style-type: none"> • The service has an approach to individuals that recognises their unique physical, emotional, 	<ul style="list-style-type: none"> • Friendships may develop based on mutual intolerances (likes and dislikes).
<ul style="list-style-type: none"> • The service respects and ensures the privacy and confidentiality of individuals, their carers and 	<ul style="list-style-type: none"> • There is often a differing recognition of privacy issues.
<ul style="list-style-type: none"> • There is a Code of Conduct for Staff & I or Volunteers which guides the delivery of services in a manner that is respectful of individuals and 	<ul style="list-style-type: none"> • What is acceptable to the parties involved often changes over time.
<ul style="list-style-type: none"> • The structures of the service create a climate of safety, which permit warmth, empathy and activities to occur. 	<ul style="list-style-type: none"> • Warmth, empathy and activities occur spontaneously.
<ul style="list-style-type: none"> • Support workers may provide companionship and friendship - within appropriate transparent 	<ul style="list-style-type: none"> • Providing companionship and friendship is not the same as being a friend.
<ul style="list-style-type: none"> • The designated service generates consultative and collaborative action from which support is planned, implemented and often evaluated in cooperation with the individual and other care givers. 	<ul style="list-style-type: none"> • There is little planning in the direction that the relationship takes.
<ul style="list-style-type: none"> • There may be a set time frame for support to be given and this is unlikely to be permanent. There 	<ul style="list-style-type: none"> • May be long-standing or short, casual or intermittent egg long - life friend versus an
<ul style="list-style-type: none"> • The focus is on addressing some of the individual's needs (egg optimal quality of life for a person with a mental illness) from within the 	<ul style="list-style-type: none"> • The occupation and health status of people only play a part in the relationship rather than being the focus.

<ul style="list-style-type: none"> Does not involve self-disclosure of personal matters by the support worker. 	<ul style="list-style-type: none"> There is a level of sharing intimate personal aspects of oneself depending on the depth
<ul style="list-style-type: none"> Involves only limited physical contact e.g. a hand shake. 	<ul style="list-style-type: none"> May have different levels of physical contact.
<ul style="list-style-type: none"> A support worker cannot overlook a situation where an individual is undertaking an illegal act. 	<ul style="list-style-type: none"> A friend may choose not to do anything about someone doing something illegal.
<ul style="list-style-type: none"> Support workers are there to help individuals move along a pathway from dependency upon 	<ul style="list-style-type: none"> Friendships may create some dependencies.
<ul style="list-style-type: none"> The designated service may require that the individual's needs be addressed before those of 	<ul style="list-style-type: none"> There may be varying levels of commitment.
<ul style="list-style-type: none"> Recognises the inequality of power in the Relationship as the individual relies on the assistance of the support worker and is therefore the more vulnerable 	<ul style="list-style-type: none"> There are a mixture of emotions shared by two people which may be intense depending on the type of relationship it is e.g. a marital relationship differs from a relationship with a friend.

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<ul style="list-style-type: none"> There is usually a statement of rights and responsibilities. 	<ul style="list-style-type: none"> There is no formal documentation.
<ul style="list-style-type: none"> There is a process to resolve complaints and/ or disputes. 	<ul style="list-style-type: none"> There are usually only informal ways to address conflict.
<ul style="list-style-type: none"> The service has policies to support people and their carers taking an active role in the planning, delivery and evaluation of the service. 	<ul style="list-style-type: none"> There is no formal evaluation of the friendship
<ul style="list-style-type: none"> There are defined and documented roles and Responsibilities for office bearers of a Management Committee. 	<ul style="list-style-type: none"> There is no Management Committee.

When working with vulnerable and disadvantaged groups of people the boundaries of a relationship may become blurred and lead to over-involvement with an individual.

Indicators of a healthy support relationship	Indicators of over – involvement in a support
<ul style="list-style-type: none"> Limits are established and are the basis for a relationship built on honesty and integrity. 	<ul style="list-style-type: none"> Giving inappropriate special status to the person at the cost or neglect of other duties.

<ul style="list-style-type: none"> • Limits also set what is acceptable and unacceptable behaviour. 	<ul style="list-style-type: none"> • Expressing affection that includes the exchange of gifts. • Providing special favours. • Becoming angry or defensive if attention is drawn to these behaviours.
<ul style="list-style-type: none"> • Support is given based on a carefully organised plan in collaboration with the individual and the designated service. 	<ul style="list-style-type: none"> • Straying from the usual provision of support without consultation with the service. • Spending time with the individual outside designated hours, or at a venue other than the usual place.
<ul style="list-style-type: none"> • Support occurs in a climate of safety. 	<ul style="list-style-type: none"> • Believing that no one else but you knows and understands the individual's needs
<ul style="list-style-type: none"> • Support and contact is undertaken with integrity, competence and consistency. 	<ul style="list-style-type: none"> • Trying to rescue the individual from their problems or situations.
<ul style="list-style-type: none"> • Trust is honoured 	<ul style="list-style-type: none"> • Keeping secrets.
<ul style="list-style-type: none"> • People have boundaries - to preserve their identities as individuals. 	<ul style="list-style-type: none"> • Sharing personal information about oneself especially personal crises.
<ul style="list-style-type: none"> • Dual relationships are not appropriate (i.e. where a support relationship exists, other kinds of relationships are avoided to reduce any role confusion and violation of boundaries) 	<ul style="list-style-type: none"> • Extending personal social invitations • Requesting they perform a task for the primary benefit of the support worker.
<ul style="list-style-type: none"> • Advocacy is provided from within a service's ethical, moral, professional or legal framework as an endeavour to uphold and defend a person's rights to equity, justice or fairness. 	<ul style="list-style-type: none"> • Becoming emotionally affected by the individual's situation and attempting to effect change, outside the designated role and without permission from either the individual or the service.

Attachment B

1. Local area coordination and development, which are broad services, including individual or family-focused case management and brokerage (disability support organisations), as well as coordination and development activity within a specified geographical area. (P 23)
2. Family-focused case management and brokerage (disability support organisations), as well as coordination and development activity within a specified geographical area. They aim to maximise people's independence and participation in the community. P23
3. An important role for the NDIS in both tiers 1 and 2 would be to strengthen voluntary links between the community and people with disabilities — to stimulate 'social capital'. The goal would be to increase, rather than crowd out existing formal and informal arrangements. For example, local area coordinators (the scheme's case managers) could help link people with disabilities to local community groups P13
4. If a person elected to stay with the NDIS care arrangements, their previous support arrangements would continue, including any arrangements with disability support organisations, their group accommodation, their local area coordinator, or their use of self-directed funding. The NDIS assessment tool would be used to determine their entitlements.
5. The National Disability Insurance Agency and its local area coordinators would monitor the use of self-directed funding. P32
6. the inclusion of local area coordinators, disability support organisations and a wider community role for current not-for-profit specialised providers p36
7. The national model and its overseeing agency would learn from the best arrangements in place around Australia (such as local area coordinators in Western Australia and the accident schemes in Victoria, NSW and Tasmania). P37
8. The Commission envisages that the National Disability Insurance Agency would have a strong regional presence. There would be local area coordinators, based in, and with close connections to, the local community, with knowledge of local providers and not-for-profit organisations, and with some scope to respond flexibly to people's needs. P38
9. It would provide support to people through local area coordinators p39
10. In the main, people's contact with the National Disability Insurance Agency would be through their local area coordinator. P39