Pathways
to Leadership

Creating a New Paradigm

Submission in response to: Productivity Commission 2011 *Disability Care and Support* Draft Inquiry Support: Canberra

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Pathways to Leadership is …

Pathways to Leadership is a not-for-profit organisation, established in 2002 as a pathway for people with a disability and their families to develop networks, enhance skills and leadership roles and further build personal capacity to share with others. As the organisation has evolved it has enrolled professionals as partners and allies and directors. The Directors have worked with families and government in all states of Australia. As individuals they are also part of other training, business and non-government organisations that have a proven record of developing innovative practices, developing skill enhancement and training courses and being influential members of both Australian and International networks. This enables and encourages linking formally and informally with their peers and allies across Australia and internationally. Community leaders build their own and others capacity for success. The organisation has completed a number of successful projects, including the development of the Pathways to Possibilities course with a grant from the Australian Government *Stronger Families* Initiative.

The uniqueness of the organisation is leadership by individuals with a disability and families working together, and with professional partners. Coming together to learn contemporary theory and practice in a way that is meaningful and relevant to them in order to plan and action a desirable future. This model is one in which the most important customers are reached through the creation of community leaders, who carry the approach forward. A further objective is to build mutual capacity enabling individuals to live within and contribute to their communities.

The Mission of Pathways to Leadership is to: *Facilitate opportunities for people with a disability and their families to lead self-directive lives, demonstrate leadership and build partnerships* We provide peer support, skill enhancement, coaching, mentoring and leadership opportunities and partnerships with professionals. Working with family and individual led organisations, support groups, professionals, service providers and government agencies. We believe in quality facilitation, our facilitators have training and/or education qualifications, and we have found that people learn most effectively from those who have had similar experiences. There are two approaches to our facilitation. The first are facilitators who have personal experience with disability – either directly as an individual with a disability, a parent or close family member, with ongoing responsibility to support family members and relatives with a disability. The second are professionals who have extensive experience in supporting individuals and families in self-directing their lives.

This approach builds and strengthens partnerships, enabling learning from each other, and sharing skills and strengths. Depending upon the course content facilitation occurs in pairs, with either the individual/family or the professional leading while the other supports. Thus demonstrating equal power relationships where the leader takes the role of specialist. We also have an extensive range of programs to provide professional development to professionals using this partnership model. The development of competence using targeted partnerships enables people with a disability and their families and those who are marginalised to enhance their image as well as their skills, through the demonstration of their competence to partners that have influence in their lives. Collaborative engagement with community, professionals and policy makers in the disability sector and the wider community will result in information exchange and consultative approaches that will contribute to social policy.

Pathways Directors and its Associates have strong alliances with international leaders in Person Centred Planning and Leadership including John O'Brien and Connie Lyle-O'Brien – Responsive Services systems - Georgia; Jack Pearpoint and Lynda Kahn – Inclusion-Network – Canada; Michael Smull – International Learning Community for Person Centred Practices and Helen Sanderson and Associates in the U.K.

Introduction

Whilst the idea of an NDIA is welcome and necessary, we have concerns that the NDIS will exchange one industry for another. The opportunity to provide feedback is also welcomed.

The disability sector has become and Industry. Where service to individuals with a disability is mainly not represented as personal caring, but by professional detachment, institutionalised bureaucracy, and imposed 'client-hood'. Professionals 'service' 'clients' within a sophisticated and complex bureaucracy. Whilst the industry may have been created with the best of intentions, however it's very complexity and risk minimisation culture have enhanced its de-personalisation.

These characteristics contradict the personal helpfulness required. This life defining 'client-hood' of disability specific human services would not be tolerated by non disabled people. The fact that society and the disability industry view caring for others as 'work' or a 'job' and as a career is a major contributing factor to the disempowering client status on the objects of their good intentions. To assess, train, program, case manage, refer, advocate, provide services to and audit those services is now the norm.

Government bureaucracies devise policies and procedures that are deemed progressive, which are however the least controversial and most likely to maintain the status quo. Large bureaucracies cannot adapt easily to change, and funding regulations so often do not meet the needs of individuals. Risk minimisation policies and procedures over-regulate people's lives and intrude on the ability of individuals with a disability to make and maintain personal friendships and have informal support arrangements.

Vast resources are expended on the infrastructure of the industry. Theory replaces theory; therapy replaces therapy; and new 'models' of service delivery replace older models. Treatment is different, the pattern remains the same. The individual with a disability is not the person next door he/she is the client in the Group House for the disabled. Human services have been responsible improvements in the lives of individuals with a disability and their families, over the last few decade however, they have also been responsible for formalised structures that replaced personal caring and connection to community. The above adapted from: Westcott, R. (2003)

Duffy (1996) refers to the Professional Gift model which describes a power system, a process by which money and the authority to make decisions are transferred from the community, thought the state to professional providers, a system operates as if it were a bountiful and benign patron too those in need.

There is a history both written and anecdotal of the control by professionals of information, knowledge and resources. These unequal power relationships leave individuals with a disability and their families ineffective and disempowered. It has created a legacy of dependence upon professionals, and 'waiting' for funding, and a feeling of hopelessness or malaise, so that there is very little pro-active action amongst individuals and families occurring.

Opportunities for information and skill building around contemporary human service theory and practice have been imparted mostly to professionals. Participation by individuals and their families has been minimal, leaving many ill equipped to plan, negotiate and direct their needed assistance.

A New Paradigm

A new NDIS needs to have a culture that sees itself as primarily there for the individuals and their families, not to meet service provider or other needs. The industry needs to take responsibility for the creation of the industry, and take into account what help and support services may need to do to change their culture to Personalisation within a service, and to support Self Direction.

If we are going to change the balance of power, then there needs to be a whole new paradigm shift and culture change within government and services about the capacity of individuals and families, and in their inherent honesty and goodness.

By viewing and treating individuals and families as having the capacity to design and structure their own supports, and who may require some support to achieve this if they so require. In fact some individuals and families may need to have support to believe in their own capacity, due to the socialisation of society who often sees both the individual and the family in a devaluing way-as part of a tragedy model. Reinforced by the attitude of professionals who have often with the best intention, helped create dependency. Professionals quite often only see the individual and family when they are in crisis, not when they are demonstrating their gifts and contributions.

The more a new system costs, the less resources people will get.

It is not enough to create a new paradigm based on transforming the old, or the industry. Peter Block, in his book Community: *The Structure of Belonging* talks about having conversations that lead to a future possibility, rather than having conversations that problem solve and only make improvements on the past. In this case the model of the industry.

Feedback to the Draft Report.

This paper is based on the premise that a new paradigm and culture change is desirable and the specific feedback provides suggestions to promote this.

Recommendation 5.1-5.9

Assessment:
If part of the objective of the NDIA is to empower individuals with a disability and families, then having a non self assessment process will reinforce the negative power relationships that exists between Government, Services and Families and Individuals Evidence from the U.K. suggests that rather than asking for more than they need, individuals and families are more inclined to ask for too little.

Families who do not use savings will voluntarily return them at the end of an annual cycle, providing they know that if their needs change they can have their funding enhanced. The anecdotal comments are “someone else needs supports”.

In Australia, we have been ‘trained’ to ask for more, because our expectation is that we will then be asked to reduce the figure, so we factor this in. It will require a culture change and a demonstrated commitment by the NDIS to ensure that re-assessment if needs change will be easy to access, with a timely funding response.

- *Figure 5.1*: The suggested Assessment Process is unwieldy and costly and another ‘assessor industry’ will be developed

- *Draft recommendation 5.4*. Much is made of the need for the assessor to be objective. Assessment tools that rely on ticking boxes are flawed. Individuals or families can be asked questions and their interpretation of how to answer may not be useful. e.g, a woman with autism who answers questions in a way that she believes others should see her life, not what is realistically occurring for her.

These types of assessments do not change the power relationships, rather they expand the professional gift model. The assessment process needs to be fair and equitable, guided by a set of principles.

The process should be person centred, focus on gifts and contribution, be forward looking as the draft recommendation has stated, considering the supports that would enable a person to achieve his/her potential in social and economic participation.

The process needs to be similar to the 9 open ended questions used in the United Kingdom, where people use a self-assessment process of articulating their goals, aspirations and resource needs, which are costed via the Resource Allocation System. During the process the self-assessment is verified.

5.6.Carer Assessment.

Feedback:

As the parent of a woman with disabilities, I do not in any way identify with the term Carer. I am a mother. Carer to me implies caring for my parents or a partner. I do not need nor want counselling – I need to have access to the support I need.

- I do not want to go to a Carer Support Centre
- I do not want to be assessed for the best training & counselling options
- Where is my decision making power?
- *I want peer support to help me plan a desirable future for my family member, and to either self direct, or identify a service that has a culture of personalisation.*
- *I would want to be asked about how supporting my family member impacts on the quality of my life, and my ability to work and have social supports-as is done in the U.K.*

Please refer to the Evaluation of In-Control in the United Kingdom.

Draft Recommendation 6: Who has the decision making power?

6.1.

Feedback:

People should have various options for exercising choice.
Be able to have cash budgets, have their funds directly into their bank accounts and purchase the supports that best meets their needs and preferences and that promote participation in the community and in employment

Disability Support Organisations: *Would among other things provide people with:*

a. *Brokering service, such as information about service providers that might be suited to the specific individual and arranging supports on their behalf (based on the person's personal plan, support package and state preferences)*
b. *Initial information about the scheme, assessment process and their rights and responsibilities (funded by NDIS)*
c. *Personal Planning*
d. *The skills and confidence to practically exercise choice*
e. *Advocacy services*
f. *Management services (such as dealing with the administrative aspects of self-directed funding, were a person to go down that route)*

Feedback:

It is of major concern that the role of service provider and disability support organisations (DSO) could overlap.

(a) (d) and (f) need to be the role of a DSO
(b) May be provided by service providers and DSO's
(c) Personal Planning – must be totally independent of any other supports as must (e) advocacy services. It is a conflict of interest for planning or advocacy to be part of a service or DSO.

There is no mention in the report of the role of peer support: Individuals and families who are successfully using services that embrace Personalisation or who are Self Directing are the most compelling role models of people having the capacity to design and structure their own supports. They can be the most effective and powerful support to others who may want to achieve similar outcomes, and who may need role models to believe in their own capacity.

Peer Support DSO's that are community based would be a desirable option. These organisations could provide (a); (b); (d); and (f) most effectively. Being local and community based accessible to individuals and families, and would be able to build information on local networks; play a role in connecting individuals and families to their community; assist and also in choosing a provider appropriate to personal requirements; would be ideally placed to provide all the options outlined in **6.6.** e.g, (1) Information; (2) support and guidance; (3) examples of innovation (very powerful as people within a peer support DSO would model such examples); (4) provide training to local case managers etc., and (5) mentor other to establish similar organisations.

There are examples across Australia of individuals and families, and peer support groups and organisations, providing professional development and training to professionals such as case managers.

Further advantages:
Community organisation have proven to be cost effective, and peer support organisations would be a demonstration of the shift in power relationships, whereby the competence of individuals and families would be clearly demonstrated. Being grass roots they would be ideal to give ongoing feedback to the NDIS as to the practical implementation of resources, and policy and could in fact contribute to the development of policy. Thereby be part of developing a system that remains as non-bureaucratic and maintaining an appropriate balance.

The Decision Making power then an really rest with the individual and their family, in a peer led organisation that provides feedback to NDIS and Government.

The writer has visited the U.K. twice and met with the founders of In-Control and other people and providers, who have been involved since the inception of the Valuing People initiative, together with individuals and families who have individual budgets.
Please refer also, Evaluation of In-Control in the U.K.

6.2.
Feedback:

- Person Centred Planning needs to be separate from all aspects of service provision.
- Plans and funding proposals would need to have a specified short turn-around time; the waiting time for assessment; between assessment and funding and time to receive funds has been a source of angst to individuals and families in the U.K.
- The proposed quick turn-around for changes to funding proposals; adding any private funds; allocate individual budget to any mix of preferred specialist and mainstream

services subject to the two points mentioned in the draft report, support choice and decision making power.

6.3. Monthly Instalments.

Feedback on Budget Cycle.

- A monthly budget cycle is not sufficiently adaptable. People with a disability need to have flexible support options, which means they may not use the same hours each week – As the report itself states, there is very little evidence of fraud, so 3 monthly is a more sensible option.
- The 10% 'bank' idea is laudable, perhaps 15% for people with high support needs when unexpected events may occur, such as illness or a temporary level of higher support than usual required would be a possible consideration.

6.4-6.5. Employing family members.

Feedback:

Whilst a trial to confirm guidelines to prevent possible exploitation is appropriate, the consideration that a family member may be the best paid person to support an individual needs to have positive deliberation as it can be a positive common sense solution. The reduction in funding allocation is a puzzle. Whilst some family members may be in a position to provide assistance at a reduced rate, if a family member needs to work for an income, and if they are the right person to support the individual, then they should receive the same compensation as any other paid supporter. For example: If a woman lives with her partner and has a degenerative disability, and her daughter needs to work part time to support her own family, then paying the daughter to support her mother to be part of her community, shop for groceries etc., etc., only strengthens family relationships. The mother and daughter spend time together, rather than the daughter working elsewhere and having to find time to be with her mother.

6.6. information about self-directed funding options.

The NDIA should:

1. *Inform people with disabilities and their proxies of the various options for self directed funding.*
2. *Provide support for people using self directed funding, including easy-to-understand guidance about the practical use of self-directed funding, including standard simple-to-follow forms for funding proposals, hiring employees and for acquittal of funds.*
3. *Promote the use of self directed funding, with examples of innovative arrangements*
4. *Provide training to local case managers and front-line staff about self-directed funding.*
5. *Encourage the formation of disability support organisations to support people in the practical use of self-directed funding.*

Feedback:

Please refer to feedback under 6.1. – Peer Support/Disability Support Organisations.

Additionally:

It is of concern that the group home model has been mentioned more than once, and there has been little discussion in the draft report about innovative arrangements.

The mention of group homes as accommodation support options, with less emphasis on innovative options is of major concern.

The Convention of the rights of persons with disabilities (2006) (CRPD) was adopted by the United Nations General Assembly in December 2007. Australia is party to seven of the United Nations' core human rights treaties, including:

- International Covenant on "Economic, Social and Cultural Rights'

- International Convention on the Elimination of all Forms of Racial Discrimination
- The Convention on the Elimination of all Forms of Discrimination against Women
- Convention on the Rights of the Child
- Convention on the Rights of Persons with Disabilities.

Each of which incorporates the right to housing and social services. Article 19 of the Convention expresses the following:

"…..recognising the right of all persons with a disability to live in the community and participate in community life with choices equal to others, including the opportunity to choose their place of residence…and

- Where and with whom they shall live on an equal basis with others
- Having access to a range of in-home residential and other community support services….and
- The personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from community"

Having to live with someone or a group of someone's that quite often you do not know, in order to '*make the money go round'* is a concept that non-disabled people would find unacceptable. Some non-disabled people have spent some times in their lives when they shared an abode, however this was usually time limited, and they were free to leave, or it was a lifestyle choice. There are some individuals with a disability who have chosen to live together because they have been friends, once again a lifestyle choice.

Families believe, or are led to believe about the 'safety' of group homes, or that if their son/daughter does not live with his peers he/she will be 'lonely'. Supported Employment or day options seem ideal, as their family member is supported according to their capacity with the inbuilt safety of supervision.

Models such as these perpetuate the concept of "us" and "them" whereby community sees the client in the group residence as 'them' and they the community as 'us' and therefore separate.

The opportunity for innovation will open the doors for many people to move from client-hood to community member. There are many stories across Australia of individuals who may require quite high degrees of assistance, successfully living in their community, contributing their gifts and skills, and being part of mutually supportive relationships. The more personalised the assistance, the less people assisted the more intimate the knowledge of the individual, their dreams, hopes and aspirations, and the less likely bureaucracy will intrude. There are many stories across Australia of individuals who received high amounts of assistance who, upon leaving a group setting, were found to need substantially less assistance than they had been receiving.

The proposed NDIA can be pivotal to innovative arrangements, even for individuals who require high degrees of assistance. Reflections on how support arrangements can occur with support from community members and friends, rather than from a formal service structure will enable individuals to have an 'ordinary life', similar societal norms, and to that enjoyed by neighbours and friends.

6.7. Offering Self Directed funding:

Feedback:

The decision whether or not an individual/family may be offered the opportunity to self direct during the assessment phase is counter productive. This should be a consideration after in depth person centred planning has occurred. As part of planning a support system may emerge, that was not evident at the time of assessment. When individuals and families are planning desirable futures, they are often surprised at the network of support that is available if they only ask. The U.K. model demonstrates that successful long-term networks of support can be developed around an individual who has no family.

6.8. Reducing risks of neglect or mistreatment.

Feedback:

Of concern is that of monitoring by case managers unless following up on a complaint.

7.3. Governance/Advisory Council-Who has Decision Making Power?

Feedback:

If an objective of the NDIA is for individuals and families to have choice and control, then an Advisory Council needs to comprise a majority of people who are accessing or are eligible to access supports from the NDIA. Once again the message of a changed culture needs to be modelled. The writer has been a member of a Ministerial Reference Group, Disability Councils and participated in reference group around specific government initiatives, including Local Area Co-ordination. Experience has demonstrated that if past imbalances are not addressed within the Advisory Council, it will be dominated by services and administrators and the consumer voice will be lost.

8.1 Supporting Consumer Decision Making

Feedback:

- Centralised Database: This recommendation needs to have a strong element of involvement by individuals with a disability and families. Including ongoing involvement in the design of the internet data base.
- Well resourced and effective provision of advice and information etc. This needs to have a leading element of peer support. Individuals and families, from their lived experience are the most qualified to lead the design and implementation of these types of services, in partnership with professionals

8.3. Quality Framework:

The NDIA should develop and implement a quality framework for disability providers, which include:

- *The development of complete, nationally consistent standards that would apply to all funded specialist providers and disability support organisations. The NDIA should monitor compliance with these standards and other regulations through a range of instruments, including graduated and rolling audits of service providers, community visitors, senior practitioners independent consumer surveys, complaints, surveillance by case managers and interrogation of the electronic disability record.*
- *Arrangements that encourage the diffusion of best practice throughout the disability sector*
- *Providing consumers with information about the quality and performance of service providers on the national internet database of service providers.*
- *Establishing an innovation fund that providers would use for developing and/or trialling novel approaches to disability services.*

Feedback:

This is establishing up a compliance based audit that is a paper based process rather than an evaluation process that monitors the wellbeing of individuals and families within a service.

Current Audit system paper processes give no indication of how life is for an individual or family. Less scrupulous service providers ensure that those Interviewed by Auditors will

paint the service in a positive light, whether the interviewee is really satisfied or not. The Audit approach seeks to assure compliance to standards and believe that standardisation equates to quality.
Once again, if the power relationships are to change, then an alternative to an audit system that has the capacity to make a culture change is required. Such an alternative has been successfully working in New Zealand for 30 years.

Standards and Monitoring Services (SAMS) of New Zealand were established in 1985. It is governed by individuals with a disability and their families. 80% of SAMS experienced evaluators, educators and researchers are people with a disability and family members who play a lead role in service improvement and conduct approximately 100 service evaluations each year, and provide training to professionals and knowledge enhancement opportunities to individuals and families. SAMS pioneered the model of Developmental Evaluation-stakeholders constructively working together using evaluation as a forum for quality improvement. It is intended to assist services to improve, and is firmly grounded in collaborative and inclusive approaches, rather than a compliance approach. SAMS primary developmental evaluation process is to influence positive change, raise consciousness and cultivate innovation. SAMS believes that the only grounded justification for evaluation is that it enables people to obtain better lives.

In a recent evaluation of SAMS, Michael Kendrick Ph.D. noted "The widely held perception of SAMS is that it is competent, has talented staff, is responsible and conscientious, fair and even handed, diplomatic, exemplary in their values and responsive when issues arise".

Kendrick also made the following comment; "SAMS is very much in sync with both the intent and detail of the UN convention on Human Rights and the New Zealand Disability Strategy, and has been so well before the Disability Strategy or Convention were conceived of. In effect, the conduct of SAMS is, as many have said, that of an exemplary proponent of the rights and dignity of people with disabilities." Kendrick M (2009)

13.1. Support Workers:

Feedback:

Subsidies for training: How will these subsidies be distributed? To services? To workers? directly? Will self directing families have the opportunity to recommend that a specific worker they employ receive a subsidy to attend a specific course such as Epilepsy or First Aid?
Anecdotal and written evidence in several countries is that families who employ directly do not always want formally trained support workers, and that training does not necessarily produce a competent support worker. What they want is values and common sense.

13.2. Police Checks:

Feedback:

All paid workers need to have a police check. Covering workers for a given period, rather than who they work for would be an appropriate cost saving and minimise bureaucracy.

13.3. Training and counselling for carers

Feedback already given under 5.6.

As the parent of a woman with disabilities, I do not in any way identify with the term Carer. I am a mother. Carer to me implies caring for my parents or a partner. I do not need nor want counselling – I need to have access to the support I need.

- I do not want to go to a Carer Support Centre
- I do not want to be assessed for the best training & counselling options
- Where is my decision making power?
- *I want peer support to help me plan a desirable future for my family member, and to either self direct, or identify a service that has a culture of personalisation.*

- *If I am self directing, I also want to be do a succession plan for when I am no longer available to advocate, and funding to partially fulfil my self direction role so it can be maintained under the direction of my family members siblings.*

Please refer to the Evaluation of In-Control in the United Kingdom.

Feedback
If an objective of the NDIA is for individuals and families to have choice and control, then an Advisory Council needs to comprise a majority of people who are accessing or are eligible to access supports from the NDIA. Once again the message of a changed culture needs to be modelled. If past power imbalances are not addressed within the Advisory Council, it will be dominated by services and administrators and the consumer voice will be lost.

Further Comments

Housing
The lack of public and suitable housing has been identified. However thought needs to be give where specific housing size and layout may enhance or detract from the support needs of the individual, e.g., physical space or layout due to the disability, such as physical support needs, anxiety, or proximity to family.
There needs to be a way for individuals to access to private rental via subsidies in their funding – where this is the only option,

Types of costs: Costs that may be seen as regular living costs should be able to be part of an individual's funding if these 'regular' costs are higher because of disability. The example of electricity given on page 67 draft recommendations is a classic example.

Culture Change within Services:
The writer visited the U.K. during 2006 and 2008. During the last visit I spoke with service providers who had successfully made culture change for personalisation within their organisations, the founders of In Control in the U.K. and Scotland, Families, Local Authorities, Members of Helen Sanderson and Associates who provide assistance to services and Local Authorities to learn the principles and practice of person centred planning, together with Michael Smull of the U.S., one of the founders of person centred planning.

They were asked what worked well, and what would they do differently:

Without exception, the comments were that;

- Initially the founders of In-Control spent time engaging the Local Authorities, and over-looked the need to engage service providers, which they then had to address
- The need for families to have peer information and support was also overlooked.

As a result, they were now developing strategies to engage service providers, and families were being supported to develop 'brokerage' services, similar to the comments made under feedback in 6.1 that there should be an opportunity for DSO's to be peer support agencies. Peer support organisations were also seen as a model that would assist in service culture change.

Thank you for the opportunity to provide this feedback.

References:

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About the Writer:
The writer is the parent of a woman of 42 who requires substantial assistance to live within her community. Together they are self-directing an accommodation support package in order for the lady to have a lifestyle similar to that valued by the general community. Including the opportunity to be part of and contribute to her community and to live in a home she chooses and whom she chooses, rather than living in a 'group' arrangement.

As a professional in the field, the writer holds a B.Soc Sci (Human Services) together with a Diploma in Training, and Assessment Systems. In the course of her career she has developed a number of consumer led organisations in Queensland. As the founding director of Parent to Parent Association Qld Inc., she developed a family driven organisation funded by Government, where experienced and suitably trained families assist others to plan desirable futures for their family members with a disability across Queensland, using person centred planning. The organisation also assists other families to develop agencies that will enable them to self-direct and has a highly positive reputation for its innovation.

In 1992 the writer was the lead project officer in a small organisation Fraser Coast Quality Lifestyles, developed by group of families and individuals to conduct a pilot project on individualised funding for the Australian Government – the then Department of Human Services and Health – now Families Health and Community Services and Indigenous Affairs. The Social Policy Research Centre, University of N.S.W. evaluated 4 of the 8 pilots and only the Fraser Coast project successfully met its outcomes.